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## **Accommodation for adults with intellectual disability: Exploring the lived experiences of ageing parent carers and the reasons behind their decision to continue to care in the family home**

Wendy Simpson  
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**Accommodation for adults with intellectual disability:**

Exploring the lived experiences of ageing parent carers and the reasons behind their decision to continue to care in the family home.

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BSocSc(CommtySt), GradCertPublicHlth

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## Abstract

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As life expectancy increases and mortality rates decrease, Australia is faced with an ageing population. This is particularly true of the population of people living with intellectual disability. Australian research has found that there is an increasing number of ageing parent-carers continuing to provide care for their adult child with an intellectual disability in the family home. Since deinstitutionalisation, many families made the choice to provide care at home, which may become a concern as they age and ask the question “who will care when I am gone?” The purpose of this study was to explore the reasoning behind decisions families made that resulted in them continuing to provide care in the family home, what barriers they experienced, and what plans they had in place for the future accommodation for their adult child with intellectual disability.

A qualitative phenomenological approach was utilised for this study, through a social constructivist worldview. Semi-structured interviews explored the lived experiences of ageing parent carers who continue to care for their adult child with intellectual disability at home. Four families were interviewed for the study.

Contrary to the findings of other studies, this study found that the degree of the disability of their adult child and the absence of informal support networks had no bearing on the decision for these families to continue to provide care at home. The families in this study perceived that the care they provide at home was better quality than the care that is provided in accommodation services. This perception was influenced by previous experiences in respite care. In addition to this, even though all of the families interviewed had wills in place, concrete plans for their son or daughter’s future accommodation and care were often vague, or non-existent other than financial bequests.

Recommendations focused on improving the first and subsequent experiences in respite care by implementing strategies to improve the quality of care, perceived or real, provided in disability accommodation. Further recommendations include the introduction of funding to allow for planning sessions for families to navigate the legal system in regards to wills, financial bequests and guardianship. Final recommendations include the introduction of further education for service providers, Local Area Coordinators and NDIS Planners to have a greater knowledge of the challenges families

face as they age yet continue to provide care, and to be better equipped to provide the information and resources to plan for the future of their adult child with intellectual disability.

**Key words** – intellectual disability, ageing parent carers, accommodation, barriers, respite

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Signed... ..

Date...16/01/2017.....

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## Acronyms

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ABS - Australian Bureau of Statistics

ACROD - Australia Council for the Rehabilitation of the Disabled

AIH - Authority for Intellectually Handicapped Persons

AIHW - Australian Institute of Health and Welfare

CAP - Combined Application Process (funding)

CSTDA - Commonwealth State-Territories Disability Agreement

DASH - Disabled Advocates and Self Help Committee

DIH - Division for the Intellectually Handicapped

DSC - Disability Services Commission

LAC - Local Area Coordinator

MICA - Mentally Incurable Children's Association

NDIA - National Disability Insurance Agency

NDIS - National Disability Insurance Scheme

NDS - National Disability Services

PWdWA - People With disabilities Western Australia

SLCG - Slow Learning Children's Group

SDAC - Survey of Disability, Ageing and Carers

WA - Western Australia

## Definition of terms

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**Ageing parent carers** – Parents aged 65 years or over, caring for a child with disability living in the same residence (Qu, Edwards, & Gray, 2012).

**Deinstitutionalisation** – Policy direction since the 1970's to move people living in institutions to community based accommodation and support (Chenoweth, 1999).

**Eugenics** – a belief in the first half of the twentieth century that people with disability were a “threat to social progress” and intellectual and physical disability was hereditary. This led to practices such as sterilisation of people with disability, and ‘ranking’ of people based on their normalcy (may be known as Social Darwinism) (Barnes & Mercer, 2003, pp. 31-32).

**Extended caregiving** – a term used to describe the care provided by parents for their child with disability into adulthood (Cuskelly, 2006).

**Group homes** – (see also shared supported accommodation) a common residence where people live requiring care and/or support; may be government or non-government run; staff are rostered to support residents in daily living and community participation (Bigby, Bowers, & Webber, 2011).

**Intellectual disability** – disability that has significant impairment in intellectual function and behaviour, varying in nature and extent, that was first evident in the developmental period of a person's life (Australian Institute of Health and Welfare (AIHW), 2008).

**Medicalisation of disability** – (medical model of treatment) defined disability as a disease, hereditary and incurable, dominated by medical professions (Gillgren, 1996).

**Normalisation** – policies that enabled people with disability to live socially valued lives through integration into mainstream society (Barnes & Mercer, 2003).

**Quality of life** – an “individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation (WHO), 1997, p. 1).

**Respite** – a term used to describe accommodation or living support “to provide a short-term and time-limited break for people with disability, families and other voluntary carers of people with disability” (The Productivity Commission, 2011, p. 23).

**Shared supported accommodation** – the preferred term for ‘group homes’

**Social model of disability** – a view that was in contrast to a “medical model” where disability is seen as something that needs medical intervention or cure, to disability being seen as socially constructed, which reflects the experiences of people with disability, rather than their impairment (Sullivan, 2009).

**Social role valorisation** – a social theory developed by Wolf Wolfensberger based on the earlier principle of normalisation, described by Wolfensberger as “the enhancement of the social role of persons or groups at risk of social devaluation” (Wolfensberger, 1983, p. 438).

*A note on the terminology used throughout the thesis – Following advice from People with Disability Australia (PWDA) and People with disabilities Western Australia (PWdWA), terminology used throughout the thesis is “people with disability”, “adult child with disability”, and “people with intellectual disability”, as a best practice model. This use of terminology places the person first, and is the most widely accepted terminology for people with disability in Australia.*

*Throughout the thesis, the term “parent carers” refers to parents who care for their child at home.*



# Chapter 1      Introduction

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Since early in the 21<sup>st</sup> century Australia has been experiencing a population growth averaging 1.5% each year as a result of natural increase (number of births over number of deaths), and overseas migration (Australian Bureau of Statistics, 2012b). In addition to this, the trend in population ageing is predicted to continue with the average age of the population and the proportion of the population over 65 years of age expected to rise substantially in the first half of the century (Australian Bureau of Statistics, 2012b).

Research conducted in the United Kingdom, the United States of America and Australia indicate that the life expectancy of the population of people with intellectual disability has increased at an even greater rate than the general population over the last 30 years (Bigby, 2010). Furthermore, data drawn from the 2006 Census and the 2009 Survey of Disability, Ageing and Carers indicate that the number of ageing parent carers with an adult child with disability in Australia will continue to increase in the future (Qu et al., 2012). This trend is supported by reports on disability service users (from the Australian Institute of Health and Welfare in 2011) revealing an increase in service users being cared for by their parents over the age of 65 years (Qu et al., 2012).

Currently, people with intellectual disability reside in the family home for “considerably longer than is the community norm” (The Productivity Commission, 2011, p. 260).

Previous studies have revealed that there is a concern that housing and support options for people with disability will be inadequate with the potential increase in population growth and ageing, causing a great deal of concern for people with disability and their family carers in regards to where they will live (Qu et al., 2012). Adequate planning for future services and accommodation provision will be required to address these projected shortages, to ensure that housing options are available for people with disability into the future. Recommendations to the Senate Community Affairs Committee in 2010 include urgent action to consider the housing needs of people with disability (Pierce & Paul, 2010).

There are significant gaps between demand and supply of housing and support services in all jurisdictions; all housing services are crisis driven; there are long waiting lists and the needs of many people with a disability and their families are ‘under the radar’ (Pierce & Paul, 2010, p. 15).

Intellectual disability can be defined as “significant impairment in intellectual functioning; difficulties in adaptive behaviour; and manifestation in the developmental period” (Luckasson et al. cited in Australian Institute of Health and Welfare (AIHW), 2008, pp. 5-6). In Western Australia (WA), people with intellectual disability total 46% of people who access disability support services, while those with physical disability total 13% (Community Development and Justice Standing Committee, 2014).

This study explores the lived experiences of ageing parent carers who continue to provide accommodation and support in the family home for their adult son or daughter with intellectual disability. This study will consider the decisions that ageing parent carers have made in respect of the future living arrangements for their adult child, in an effort to understand the experiences of the families and the reasoning behind the decisions they have made. The history of accommodation services for people with intellectual disability, and the national and state policies that have influenced disability services, lay the foundation of the thesis. A literature review was conducted to examine previous research undertaken in this field, which did not reveal any current studies in WA, though it is thought that recurrent themes in the previous research elsewhere may be pertinent.

The theoretical framework chosen for this study is from the viewpoint of social constructivism, utilising a phenomenological approach. The qualitative research method selected was through semi-structured interviews with ageing parents caring for their adult child with intellectual disability at home. For ethical purposes, participants from my own organisation were excluded (a disability service provider in Perth), to ensure that there is no misconception that participating may affect services delivered to the client. A structured data analysis approach was utilised for this study, with analysis assisted by NVivo (a software package), supplemented by manual analysis.

Following the presentation of the results of the interviews from the participant families, the discussion section revisits the research questions and interprets the results to describe the significance for parent carers who find themselves continuing to provide care as they age. The final chapter of the thesis presents recommendations based on the results of this study, supported by the main factors that emerged as an influence for ageing parent carers to continue to provide care in the family home for their son or daughter with intellectual disability.



## **1.1 Background to the study**

The social and cultural construction of disability is influenced by the use of language, how society interprets and understands 'disability', and the way society labels or describes people with disability. In history, language referring to people with disability, including 'feeble-minded', 'mentally deficient', 'cripple', 'idiot' and 'spastic', affected the lives of people with disability and influenced the way society treated them. The use of this sort of language is no longer acceptable, and yet they are often still used today to abuse or ridicule others (Barnes & Mercer, 2003). Cocks and Allen (1996) argue that the use of devaluing language, with connotations of inferiority, contributed to the oppression that people with disability experienced. For this reason, historical aspects of disability, how society has constructed disability, and the powerlessness and devalued roles in society that people with disability have been forced to accept are important to this study.

This study sought to understand the lived experiences of the family carers, who themselves have witnessed and encountered the societal negativity and oppression that their family members with disability may have experienced. In lieu of the actual voices of people with disability themselves, this study aims to gain a better understanding of the lives of ageing parent carers, and how society, policy makers, experiences and circumstances have influenced the decisions they have made when considering future accommodation options for their adult child with intellectual disability. The experiences and perceptions of parents provide a valuable contribution to the understanding of lives and future of their loved ones, as many people with intellectual disability may not have the ability to voice their own desires for their future. Therefore, it is these stories and lived experiences from their parents who act as proxy for them. Cocks and Allen (1996, p. 284) acknowledge the limitations to this approach;

Whatever observations might be made of the experiences and life conditions of people with intellectual disabilities, any concepts and theories which result from that observation are merely partial interpretations that can never completely capture the lived experience of actual people with intellectual disabilities.

Opinions regarding people with intellectual disability are formed through our own life experiences, our observations of and exposure to formal service systems, including physical environments, where the services are located within communities (often closely together) and the historical “practices of control and treatment” (Cocks & Allen, 1996, p. 289). Wolfensberger (cited in Cocks & Allen, 1996) held a belief that the physical environment, the people sharing the environment, and the “activities and practices that were imposed upon them” were as important as the language used when referring to people with intellectual disability, and influenced the creation of the social roles for people with disability as society saw it (p. 290).

The establishment of public institutions were on the rise throughout the nineteenth century, and life-long incarceration was considered imperative to groups in society who would not benefit from educational care (Megahey, 1996). While the colonisation of WA in the early nineteenth century saw a dramatic growth in the population, people with intellectual disability and mental illness were largely hidden from society. The following section provides a brief history of accommodation for people with disability in WA since colonisation to 2016.

### ***A brief history of accommodation for people with disability in WA***

Due to poor or incomplete record keeping there is some difficulty in accurately analysing the social history of disability in early colonised WA. Furthermore, any records kept are from the perspective of the authorities. Hudson-Rodd and Farrell (1998) state that in Western Australian history the voice of the ‘inmate’ is not often heard and that “most records are scripted by the keepers and not the kept” (p. 153). Incarceration of people with intellectual disability in WA was well established by the mid-nineteenth century. The dominant view was that people with intellectual disability, along with people with mental illness, were regarded as a “threat to society” (Megahey, 1996, p. 24).

The Round House Gaol in Fremantle is where WA’s first residents with intellectual disability were thought to be housed (Hudson-Rodd & Farrell, 1998). Records have shown that many of the inmates of the Round House Gaol who were classified as “lunatic”, “sick lunatic” or “insane”, were transferred there from the Colonial Hospital in Perth (forerunner to the Royal Perth Hospital) (Maude, 2013). Institutional architecture in the nineteenth century focused on containing and controlling inmates,

whether ‘criminal’ or otherwise, and this is reflected in the panopticon design of Fremantle’s Round House Gaol, the first permanent building in the new colony of WA (Hudson-Rodd & Farrell, 1998). Another example of the panopticon design is the prison built in 1864 on Rottnest Island (18kms off the coast of Fremantle), for Aboriginal prisoners (Lydon, 2014). A panopticon design allows for observation of inmates from a single vantage point based at the centre of the building, hence “a means of control and containment” in itself (Hudson-Rodd & Farrell, 1998, p. 156).

Plans for a purpose built asylum were in place by the early 1850s when overcrowding in the Round House Gaol, and the increase in its ‘insane’ population, led to the establishment of a temporary asylum known as ‘Scott’s Warehouse’ located in Fremantle (Maude, 2013). Maude (2013) considered this moment in 1857, with the transfer of ten ‘convicts’, as the commencement of the history of the asylum in WA. At Scott’s Warehouse, under the management of the surgeon of the new colony Dr George Attfield, seclusion and physical restraints were seen as a last resort, and therapy, ‘amusement’ for the inmates, and employment within the asylum was the preferred method of ‘treatment’ (Maude, 2013).

### ***The Fremantle Asylum (1861 - 1909)***

Construction of the Fremantle Asylum (now the Fremantle Arts Centre) began in the late 1850s, built by the convict population. The penal roots of the system meant that patients were treated as prisoners, and female and male occupants were separated. Some patients were as young as nine years of age. Medical conditions of the inmates included “perceived social deviancy, be it criminality, poverty, depression, alcoholism, mental illness or activities then considered sexually deviant to be labelled ‘lunacy’” (The Fremantle Arts Centre, n.d., p. 3). Perceived moral and economic danger that some groups of people posed to the colonial population resulted in the asylum housing people from all walks of life, including those considered ‘paupers’ and those that the community considered as an ‘inferior race’ (such as Asian indentured servants at the conclusion of their contracts) (Megahey, 1996). Megahey (1996) states that “once in the asylum, people with intellectual disabilities remained there”, with many spending most of their lives within its walls (p. 41).

The *Lunacy Act 1871* was introduced to “provide the safe custody of, and prevention of crimes by, persons dangerously insane; for the care and maintenance of persons of

unsound mind” (Government of Western Australia, 1871), contributing to the confounding of mental health and intellectual disability. Severe overcrowding during the 1870s saw the population of the asylum rise from 45 to 119 inmates by 1887, and a subsequent enquiry into conditions at the asylum in 1898 led to the repeal of the earlier 1871 Act and introduction of *The Lunacy Act 1903*, resulting in the building of the new asylum in Claremont early in the 20th century (Megahey, 1996).

### ***The Claremont Hospital for the Insane (1907 – 1972)***

As a result of the inquiry and the new regime of ‘rehabilitation’ for the new century, the Claremont Hospital for the Insane opened in 1907 on 92 acres of Crown land in the suburb of Claremont in Perth (Gillgren, 1996). Reflecting the “developing international trend towards medicalisation of both intellectual disability and mental illness”, the ‘hospital’ was administered by doctors and staffed by nurses (Gillgren, 1996, p. 57). Dr Sydney Montgomery, Superintendent, was an advocate of eugenics, and believed that mental illness and intellectual deficiency was hereditary, therefore ‘patients’ in the hospital were separated not only by sex, but also by their diagnosis. The separation by diagnosis was reflected in the architecture of the hospital, with wards for the “violent and noisy...sick and infirm...recent and acute...quiet and chronic”, while ‘epileptics’ had their own ward (Gillgren, 1996, p. 59).

Wards were large scale and afforded no privacy. Their conception was firmly rooted in the economies of scale identified with contemporary general hospitals, and the effect can only have been dehumanising. Early photographs show them to be devoid of individuality and decoration. The windows were barred. Beds were lined up in regimented rows. Food was consumed en masse and bodies were washed en masse (Gillgren, 1996, p. 58).

In 1922 the Royal Commission on Lunacy raised concerns that Claremont was not suitable, accommodation was inadequate, with allegations of mistreatment of the patients (Gillgren, 1996). The Royal Commission made recommendations regarding the maximum number of patients (1,200) and recommendations for modifications to the building to allow for adequate facilities and ventilation (Angwin, Jackson, & Jones, 1922). The Royal Commission also recommended the planning and building of future new hospitals for the insane.

During the 1920s, there were 12 other facilities in addition to the Claremont Asylum being run for people with intellectual disability in WA. These were privately owned and operated, and many did not outlast the decade (Gillgren, 1996).

### ***Moving into the community (1950 – mid 1960)***

While the 1903 Lunacy Act differentiated between mental illness and intellectual disability, little was done to demarcate the treatment that people with disability received in accommodation services. With the formation of the Slow Learning Children's Group (SLCG), and other parent led groups in WA in the early 1950s, new models of support and accommodation were introduced (Disability Services Commission, n.d.).

In 1952, the Nathaniel Harper Homes were opened in Guildford, to provide accommodation and training for 50 children with intellectual disability moved from the Claremont Hospital for the Insane (Gillgren, 1996). The homes were government owned and run, but made possible following a donation from Mr Nathaniel Harper, who had a child with disability. The buildings were not purpose built, but were renovated and modified from homes built earlier in the century.

In 1952 the SLCG focussed on education, assessment, therapy and support for children with mild to moderate intellectual disability and their families, and opened the activity centre Minbalup in 1954 (Gillgren, 1996). In 1961 the SLCG opened a new assessment centre in West Perth named 'Irrabeena'. Gillgren (1996) states that until 1965 "the only positive outcomes...were the intervention of parents in the politics of disability, in the form of the SLCG, and the establishment of the Nathaniel Harper Homes" (p. 87).

Other parent led groups were also founded in the early 1950s. In 1954, following an article in the *Daily News* (a daily paper produced in Perth until 1990), parents with children with more severe disability formed the Mentally Incurable Children's Association (MICA), with the support of the then Health Minister Mr Emil Nulsen (Davidson, 1993). Nulsen Haven was officially opened in 1956 in Redcliffe, named in honour of the Health Minister, the first permanent home of its kind in Australia (Davidson, 1993). Nulsen Haven also offered respite for families supporting a child with severe disability at home. Throughout the 1950s, discussions were held between the SLCG and MICA to explore amalgamation, however opposition to the move on the basis of differences in their purpose (SLCG offered support and training for 'slow learning children', and MICA offered support for children with severe 'incurable'

intellectual disability) ended the discussions and the “two organisations continued to grow and develop as independent entities” (Davidson, 1993, p. 15).

The poor living conditions in the Claremont Hospital for the Insane was still a topic for debate in the early 1960s, and the recommendation was to remove people with intellectual disability from Claremont to accommodation that was centred on training and active treatment (Gillgren, 1996). Public sector accommodation facilities funded for the purpose of providing additional residential services for people with intellectual disability included new accommodation buildings at the Whitby Falls Hostel, which opened in 1958 (originally established in 1897 as an annexe to the Fremantle Asylum) (Gillgren, 1996). The new buildings at Whitby Falls Hostel included facilities for occupational therapy, with partitioned ‘wards’ that housed only eight beds, quite different to the large scale dormitories in Claremont (Griffiths Architects, 2013). The treatment for mental health patients was also becoming community based, with outpatients, day hospitals and beds on psychiatry wards in general hospitals being favoured over custodial care (Griffiths Architects, 2013).

*The Lunacy Act 1903* was repealed by the introduction of *The Mental Health Act 1962*, which advocated for “active early treatment” and sought alternative forms of accommodation for “lesser afflicted patients within the community” (Gillgren, 1996, p. 82). The hostel style accommodation similar to Whitby Falls became an integral part of the rehousing of people from the Claremont Hospital for the Insane that began in the late 1960’s (Griffiths Architects, 2013). *The Mental Health Act 1962* made provisions for the building and establishment of accommodation facilities and day hospitals to reduce the overcrowding at Claremont, and included the new accommodation facility and establishment of the Pyrron Training Centre in 1966, located in Eden Hill in Perth’s eastern suburbs (Gillgren, 1996).

Despite Acts of Parliament (1903 and 1962) that were supposedly introduced to improve the lives of people with disability and people with mental illness, Gillgren (1996) states that the influences of “economics, bogus science in the form of eugenics, and the continued failure of authorities to recognise the differences between mental illness and intellectual disability, and the medicalisation of residential care” did little to improve quality of life or dignity for this group of people (p. 87).

### *Deinstitutionalisation, normalisation and social role valorisation - 1960s to 1990s*

Prior to the 1960s, disability in western societies was seen as a “personal tragedy and a social problem or ‘burden’ for the rest of society” (Barnes & Mercer, 2003, p. 1). By 1960 the voices of people with disability were beginning to be heard, with calls for policy changes for independent community living, as opposed to residential institutions and accommodation in large scale facilities (Barnes & Mercer, 2003). This period heralded the start of ‘deinstitutionalisation’, and an era in disability services around the world greatly influenced by the writings of Nirje (1969) and Wolfensberger (1970s), and the principle of ‘normalisation’ (Chenoweth, 1999).

Normalisation was an ideology, a principle defined by Nirje (cited in Chenoweth, 1999, p. 83) as “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society”. Since most people in the community live in homes, normalisation was exemplified by the closing of institutions and rehousing of people with disability into accommodation based in communities (Dempsey & Nankervis, 2006). With the publication of *Changing Patterns of Residential Services for the Mentally Retarded* in 1969 by the committee headed by the United States President John F. Kennedy, worldwide change was occurring in regards to rights and services for people with disability. The principle of normalisation was later used as a ‘basis’ by Wolfensberger in 1983 in the development of the social theory of “social role valorisation”, defined as “the creation, maintenance and defence of valued, social roles for people, particularly those at value risk, by the use, as much as possible, of culturally valued means” (cited in Chenoweth, 1999, p. 83).

Internationally, normalisation and the rights of people with disability influenced the introduction of the *United Nations Declaration on the Rights of Mentally Retarded Persons* in 1971 and the *Declaration on the Rights of Disabled Persons* in 1975 (Chenoweth, 1999). In Australia, the *Handicapped Persons Assistance Act 1974* was introduced, repealing much of the legislation previously introduced in Australia for people with disability. Later, in the 1980s, Australian Federal and State Governments were influenced by the principles of normalisation and social role valorisation, which underpinned the *Commonwealth Disability Services Act 1986* (Chenoweth, 1999).

With deinstitutionalisation and the new concept of normalisation now on the agenda, and human and civil rights for people with disability influencing attitudes, care and services, the period from 1960 and leading up to 2000 saw major changes within Australia and around the world (Stella, 1996). In Perth, Pyrton Training Centre had opened in 1966 offering alternative accommodation for people with intellectual disability to the Claremont Hospital for the Insane, which would assist to reduce the overcrowding at the institution. However, Pyrton still served to segregate people with intellectual disability from the rest of the community, though with a focus on training that might enable people to undertake roles in society that could reduce the financial ‘burden’ on social welfare costs (Cocks & Allen, 1996). From 1967 to 1972 children and young adults were moved from Claremont to Pyrton to undertake education and training, while adults were moved to Croyden in Subiaco from 1968 (Stella, 1996). Devonleigh in Peppermint Grove, a former maternity home, also provided accommodation for people with intellectual disability from 1977 - 1987 but had received criticism as unsuitable premises, and therefore closed in 1987.

In 1964, the Mental Deficiency Division (MDD) of Mental Health Services was created, and took over the responsibility of the operation of Irrabeena (the SLCG assessment centre) (Stella, 1996). WA was considered as more progressive than other states, and operated disability services utilising the principle of normalisation with “little interference” from the other states of Australia (Stella, 1996, p. 98).

In 1972, The Claremont Hospital for the Insane was separated into Graylands Hospital for Mental Health and Swanbourne Hospital for people with intellectual disability, partly with the intent to reduce the stigmatization of people with disability living within Claremont Hospital (Stella, 1996).

However, the move to hostels in the community from Swanbourne was not all positive. Stella (1996) writes of the conditions in hostels established throughout the 1970s and 1980s, and is critical of the ‘institution like’ conditions:

The establishment of hostels as a part of the movement to relocate the people from Swanbourne was certainly beneficial to people who would otherwise have spent their lives in an institution. Others have suffered as a result of overcrowding, community prejudice and a poor quality of building. All the hostels – by nature of their administration, routines, staffing, numbers of



residents and congregation and segregation of people with similar disabilities – remained mini-institutions. The worst perhaps were the converted dormitories at Pyrton, one of which still housed over 60 people in 1990 (Stella, 1996, p. 110).

The Mental Deficiency Division was renamed the Division for the Intellectually Handicapped (DIH) in 1977, which ran hostels throughout WA (in addition to Swanbourne), and was responsible for policy development to keep people living in their own homes, or moving them from hostels into the community (Stella, 1996).

Legislation that affected people with disability during the early 1980s included the Equal Opportunity Act (1984) and an amendment to this Act in 1988, and the Authority for Intellectually Handicapped Persons Act (1985) (Disability Services Commission, n.d). The introduction of the Commonwealth *Disability Services Act 1986* reflected a new approach to service delivery for people with disability, and legislated new changes to Commonwealth funding eligibility. This new policy was intended to “break down institutions and institutional facilities into smaller, community based units” which meant that organisations, to be eligible for Commonwealth funding, must close their hostels and provide new ‘group home’ accommodation for their residents (Davidson, 1993, p. 63).

By 1986 the DIH was again renamed and became the Authority for Intellectually Handicapped Persons (AIH) (Disability Services Commission, n.d) which was also responsible for group homes, duplexes and support for people living in their own homes. Church run homes and those run by the SLCG were scattered throughout Perth (Chenoweth, 1999). Nulsen Haven had also begun a ‘transition plan’, and 1989 saw the first of the residents move out of the Nulsen Haven hostel and into community group homes (earlier in 1987 six residents from an AIH waiting list had moved into an ‘experimental group home’ run by Nulsen Haven, though they were not Nulsen Haven past residents) (Davidson, 1993). In 1992, the last of the Nulsen Haven residents moved out of the hostel and into community based group homes.

### ***Criticism of the move to community***

The closing of the hostels and move to community based homes was not without its problems. One of the criticisms of deinstitutionalisation was a “focus on bricks and mortar” and the difference between a physical presence in the community and actual

‘participation’ in community life (Chenoweth, 1999, p. 87). Hamilton (cited in Chenoweth, 1999, p. 87) suggests that:

A possible rationale for this relative neglect of community participation is the underlying driving force of economics rather than values or ideology in many earlier deinstitutionalisation programs. Under such an imperative, the main focus of the exercise is to close the institution and merely ‘place people out’ rather than attend to deeper issues such as quality of life in the community.

When defining deinstitutionalisation, a narrow view may be the focus on the closure of institutions and alternatives in accommodation in the community, however a “broader perspective would consider deinstitutionalisation in terms of societal change and individualised support for people with intellectual disability to live in and participate in the community” (Bigby & Fyffe cited in Wiesel & Bigby, 2015, p. 14).

Furthermore, Bostock and Gleeson (2004) highlight the concern that people with intellectual disability may not have had the choice of housing that they would prefer. Due to the focus in Australia of normalisation principles, choices were often overlooked, and Australia’s housing choices for people with intellectual disability leaving institutions and hostels was centred on ‘group home’ accommodation. Group homes can be described as single ‘normal’ homes in ‘normal’ neighbourhoods, with live-in staff and shared by others with intellectual disability (Bostock & Gleeson, 2004). There have been suggestions that in Australia, deinstitutionalisation for people with intellectual disability moved slower, and was commenced later, than other Western Countries (USA & UK) (Bostock & Gleeson, 2004; Young & Ashman, 2004). However, Bostock and Gleeson (2004) state that the process was more rapid in Victoria and WA than the other states. Deinstitutionalisation is discussed further in the literature review.

### ***Disability reform since the 1980s***

Reform in disability services since the early 1980s in Australia occurred at national, state and territory level to develop strategies to improve the lives of people with disability. Since 1981 the Australian Bureau of Statistics (ABS) has been conducting regular surveys to measure the prevalence of disability in Australia, provide information regarding the number of carers of older people and people with disability and the support required for their care, and to provide a demographic and socioeconomic profile

to compare to the general population (Australian Bureau of Statistics, 2012a). The information from this survey, the Survey of Disability, Ageing and Carers (SDAC), is used to assist public and private sector agencies to plan services and develop future policy direction and reform for people with disability, older people, and their carers, on a state and federal level.

The following subsections describe some of the contemporary reforms in the development of disability policy and strategies from a state and federal perspective since the 1980s, with a particular focus on those pertinent to accommodation for people with disability.

### ***National strategies and policies***

With the election of a Federal Labor Government in 1983, Australian disability programs and services came under review, and a commitment was made to reform disability services to be more inclusive, to encompass deinstitutionalisation strategies, and to allow integration and access for people with disability into mainstream services and society (Lindsay, 1996). The consultation process with families, carers and people with disability that ensued resulted in a critical report in 1985. Following the review, it was apparent that State and Federal Governments lacked coordination of disability policies, and a complete review of all programs for people with disability was required. The *Disability Services Act 1986* was a driver of the recommendations that resulted from the review (Lindsay, 1996). In addition, several national peak bodies were established following the Labor Government's election in 1983, including the Disability Advisory Council and the Office of Disability.

The implementation of the *Disability Services Act 1986* heralded the collaboration of national and state disability services and programs, and provided Commonwealth funding to the states for not-for-profit organisations already providing disability services (Lindsay, 1996). By the end of the 1980s the *Disability Services Act 1986* had enabled people with disability to move to community-based housing from institutional accommodation. However, there was some opposition to the Act led by the Australian Council for Rehabilitation of the Disabled (ACROD) (Lindsay, 1996). This group criticised the large scale move of people from institutions into community housing, maintaining that their quality of life diminished as opposed to improving.

Modifications to the *Disability Services Act* in 1992 and 1994 saw the deadlines for disability service providers to operate within the Act extended, and the introduction of the *National Disability Services Standards*. In the early 1990s the Disability Reform Package was implemented as a result of the Social Security Review in the late 1980s. The review saw the development of the *Commonwealth-State Disability Agreement 1991*, intended to “develop a national, integrated disability services system”, the *Disability Discrimination Act 1992*, and the *Commonwealth Disability Strategy 1994* (Lindsay, 1996). All of these policies contributed to the moulding of disability services, both nationally and state based. In the 21<sup>st</sup> century the *Commonwealth State/Territory Disability Agreement* third Agreement 2002-2007, specified the responsibilities of Commonwealth Government and the State Governments, allocating accommodation services and respite services within the jurisdiction of the states (Australian Institute of Health and Welfare (AIHW), 2007).

In 2008, a public consultation process informed the development of the *National Disability Strategy 2010 - 2020*, to direct collaborative action between Federal, State and Territory Governments and “to close the gap between the lived experience of people with disabilities and the rest of the Australian community” (The Productivity Commission, 2011, p. 1). Following the distribution of the discussion paper and invitations to communities to comment at public consultation meetings, the resulting report was *Shut Out: The experience of people with disabilities and their families in Australia*, released in 2009.

Intended as a ten year plan, the *National Disability Strategy 2010 - 2020* is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), which was ratified by the Australian Government in 2008. Article 19 of the CRPD states that “persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement” (United Nations, n.d.). The *National Disability Strategy* identified areas for action to further advance reform within the disability sector, which included the continued development of accommodation options that provide support for people with high and complex needs, taking into consideration supported and community living options, and support for family living choices (Australian Government, 2009).

### *Western Australian strategies and reform*

Following the Federal Government's commitment to reform in 1983, WA commenced reform of disability services. Support for disability services included funding for a Disability Resource Centre in 1984, operated by the Disabled Advocates and Self Help committee (DASH), which offered access to resources and enabled control over services for people with disability in WA. In 1985 DASH amalgamated with two other agencies and formed People with Disabilities (WA) Inc. (PWdWA) (People With disabilities WA Inc, n.d.). PWdWA is the peak consumer disability organisation providing systemic advocacy, consultation and input into legislation, policies and service provision for people living with disability in WA. The organisation is operated by people with disability or their carers.

Since 1986 reforms in WA have been directed towards promoting rights and inclusion in the community and in doing so led the way in disability service provision in Australia. In 1988 Local Area Coordination (LAC) commenced in rural WA in Albany, and introduced in Perth in 1991 (Disability Services Commission, n.d.). The purpose of the LACs is to actively involve people with disability in their own decision making and assisting them to develop links to communities and available community services (Corr et al., 2013). The LAC model was later adopted by other states in Australia and by other countries around the world. The amalgamation of two agencies (AIH and the Bureau for Disability Services) resulted in the establishment of the Disability Services Commission (WA) in 1993, following the proclamation of the *Western Australian Disability Services Act 1993*, which addressed inequality, rights, and accommodation and employment choices among the items for reform (Disability Services Commission, 2009). This new state department (and new Minister) was the first government department in Australia that was specifically for people with all disabilities (Disability Services Commission, n.d)

The introduction of the *Commonwealth State Disability Agreement* in 1991 saw improved data collection of nationally significant data related to disability, in an agreed method (Department of Family and Community Services, 2004, p. 5). Improvements were made to the agreement and the second agreement was finalised covering the period 1997 – 2002. Data collection was again a focus. A redevelopment process began in 1999 which would provide federal and state governments with the number of people with disability receiving services and information regarding service provision

(Department of Family and Community Services, 2004). The third agreement (renamed the *Commonwealth State-Territories Disability Agreement* [CSTDA]) strengthened the two previous agreements. Improved performance reporting was introduced to affirm the commitment made by the states and territories to “build inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of life” (Department of Family and Community Services, 2004, p. 3).

In WA, under the guidance of the Disability Services Commission (DSC), *Policy Priority 4* of the CSTDA included an *Accommodation Blueprint* for the five years covering 2003 – 2008. The blueprint was intended to respond to the accommodation needs of the population living with disability in WA into the future, and seek additional funding to support growth of accommodation services to satisfy unmet demand (Department of Family and Community Services, 2004). Local Area Coordination was also recognised as playing an important role in the provision of assistance and support for people with disability in WA.

In 2007 the Disability Health Check committee commenced a study which was intended to inform future directions in disability services in WA through an environmental scan and information gathering process to “shape the future and the types of opportunities and challenges that will impact on the lives of people with disabilities, their families and carers” to 2025 (Banks-McAllister, 2008). The study informed the *Count Me In* strategy released by the DSC in December 2009, which identified common themes indicating areas of concern for the future of disability services.

For the question “*Describe your vision for the lives of people with disabilities, their families and carers in 15 to 20 years’ time*”, a theme of ‘independent living’ emerged from the responses to the questionnaires. Participants indicated concern for the need for their child with disability to live independently away from home, in supported and adequately funded accommodation (Banks-McAllister, 2008). Responses stated that carers need “peace of mind on who will care when I’m gone” (Banks-McAllister, 2008, p. 7). In addition to this response, participants in the survey held aspirations that the future lives of people with disability include inclusion in community life, with their strengths and contributions to society recognised.

The questionnaire also asked the participants “*What are your fears or concerns for people with disabilities, their families and carers over the next 15-20 years?*” ‘Service

delivery' and 'care and family support' were key themes revealed as a result of this question, highlighting a concern that 'best practice models' were not communicated to families appropriately and "families need to be told that it is not good for people with disabilities to stay with their families forever" (Banks-McAllister, 2008, p. 26). Ageing parent carers, family isolation, the role of women as carers, poverty, stress and carer burnout were all highlighted as concerns of the participants.

When the *Count Me In* strategy was released in 2009, 13 priority areas had been identified to achieve the vision of "all people live in welcoming communities that facilitate citizenship, friendship, mutual support and a fair go for everyone" (Disability Services Commission, 2009, p. 4). One of the priority areas, *Pathways to strong, supportive partnerships with families and carers*, identified that an area of concern for carers is the need for the development of a long term strategy to ensure that alternatives to living in the family home are supported when the carer ages and is no longer able to provide appropriate care (Disability Services Commission, 2009, p. 28). This pathway highlighted the need for information and assistance for families to plan the future accommodation for their family member with disability, to better manage transition and crises as carers age.

### ***The National Disability Insurance Scheme (NDIS) 2014 - 2016***

More recently, in response to the Productivity Commission Inquiry Report *Disability Care and Support* released in 2011, following investigation into the unmet demands for disability services in Australia, a new scheme was proposed to provide financial support for all Australians living with disability (The Productivity Commission, 2011). This new national scheme, the National Disability Insurance Scheme (NDIS), would operate similar to Medicare in Australia and provide funding to enable people with disability to have equal and adequate access to supports, information and equipment, to enable choice and control over their lives (The Productivity Commission, 2011). The Productivity Commission acknowledged that as people with disability have longer life expectancy, there may be a time when they will outlive their parents and require other forms of support (The Productivity Commission, 2011). The report recognised that there were large gaps in availability of appropriate accommodation, forcing people with disability to remain living with their parents, instead of accessing independent supported accommodation earlier in their lives.

The NDIS focuses on individualised, person-centred care and funding, and may enable people with intellectual disability to make choices for their future accommodation (Wiesel & Bigby, 2015). However, it may not be that simple.

The NDIS will not take responsibility for delivery of affordable housing for all of its participants. While investment by the NDIS in development of new affordable housing supply will be substantial, it would require substantial leverage from other sources in order to meet demand (Wiesel & Bigby, 2015, p. 6).

While group home accommodation has been the dominant model for people with intellectual disabilities since deinstitutionalisation, there is evidence to suggest that more families are considering individualised supported accommodation options (Cocks, Thoresen, Williamson, & Boaden, 2014). The NDIS may provide this opportunity.

The Productivity Commission report also included recommendations that provide support for family carers, suggesting that informal family carers should receive their own assessment of needs to enable them to continue with the caring role and have access to counselling and respite. Recommendations were also made to consult with families during the assessment process to “explore the need for assistance with long-term planning, particularly for adults with cognitive impairments living at home with elderly parents (The Productivity Commission, 2011, p. 340). The report recognised the uncertainty and anxiety that people with disability and their informal carers experience regarding the adequacy of future funding to enable lifelong support when the informal care provided at home is no longer feasible (The Productivity Commission, 2011).

The NDIS began implementation across Australia at trial sites from mid-2014, and anticipates full national coverage by 2020. However, in order to “preserve and enhance the investments that WA has made in its disability sector” the Federal Government signed an agreement to trial two comparative service delivery models in WA (Commonwealth of Australia, 2014, p. 3). The aim is to learn from the two trial delivery models, resulting in the best possible model to be chosen for implementation in WA, and also to “inform the national roll-out of disability reform” (Commonwealth of Australia, 2014, p. 2). Local Area Coordination, an integral part of disability services in WA since the late 1980s, was incorporated into both the National NDIS model and the WA NDIS My Way model.



The agreement term was for a two-year trial period, from July 2014 to June 2016. Disappointingly, an agreement had not been reached by early 2016, so a decision was made by the Federal Government to extend the trial period for a further year. A joint media release from the Federal and WA State Governments in Dec 2016 announced a bilateral agreement to operate a nationally consistent NDIS model run by the WA Government (Government of Western Australia, 2016). The agreement is to meet 11 conditions to maintain national consistency within the WA run scheme, while building on the existing strength of the WA disability sector (Government of Western Australia, 2016). The NDIS transition to this new model in WA will commence in July 2017.

## **1.2 Significance of this study**

This study will extend existing knowledge and provide a foundation for services for people with intellectual disability and their carers that are responsive to the perceptions of this sub-group of service users. A goal of this study is to understand the barriers to sourcing accommodation and planning for the future for people with intellectual disability who reside at home with ageing parents. It is important that service providers have an understanding of what these barriers are so that assistance with planning for the future incorporates strategies that take the parents' concerns into consideration. As a result of increased future planning behaviours, this study has the potential to smooth transition from the family home at a time of crisis and avoid the move to unsuitable accommodation. Bibby (2012) found that "professional intervention will come as a response to crisis at a time of personal devastation and loss, and future living arrangements will be based on what is immediately available rather than what is wanted" (p. 104).

This study will also provide valuable information for policy development to address the barriers families face as they age and need to access information regarding guardianship, wills and accommodation funding available to their adult child. For future researchers, this study will identify some gaps in existing knowledge that would benefit from further research and greater understanding.

### ***Statement of purpose***

The purpose of this study is to understand the lived experiences of ageing parents of adults with intellectual disability whom they continue to support in the family home in Perth, WA. I hope to gain an understanding of the decisions regarding future living

arrangements that are made by parent carers, what barriers are in play that hinder future planning, and what plans have been made (if any) for the time that the parent is no longer able to provide care.

Prior to undertaking this study, my assumptions about the barriers these families face that prevent their adult child with disability to live independently include –

- lack of information of options available and lack of suitable accommodation,
- unsure of who to approach to gain information, and lack of support in doing so,
- lack of funding available, or
- cultural or values based decisions.

When conducting phenomenological research, it is a benefit that the researcher has some understanding of the phenomenon experienced by the participants. LeVasseur (cited in Cresswell, 2013) ascertains that bracketing of personal experiences and “suspending our understandings in a reflective move that cultivates curiosity” may assist the researcher to decide how personal assumptions and understandings of the phenomenon will be used in the study (p. 83). The ideas that drive research are borne from our own background knowledge, so having some background understanding of the phenomenon will help a researcher to investigate ‘ideas’ and select suitable samples for the study (Emmel, Seaman, & Kenney, 2013).

Before undertaking this research, I had personally worked in the disability sector in WA for several years. My interest in the research topic, and the reason why I chose this research topic, stems from conversations with families and parent carers who themselves raised concerns over their future and the future of their adult child with intellectual disability. It is clear that every situation is unique, but most families expressed apprehension in regards to the future.

### ***Research questions***

The research focused on a central question –

***What factors influence the decisions made by ageing parent carers of adults with intellectual disability to continue to provide care and support in the family home?***

Sub questions explored through appropriate open questioning include –

- ***Is there an informal network (family and/or extended family and friends) who assist with the provision of support in the home?***

- *Does the person with disability currently access paid services for personal care, social and/or recreational purposes?*
- *Does the person with disability access respite options for accommodation, or has accessed respite in the past?*
- *What are the barriers, either perceived or actual, that have influenced decisions regarding current or future care in shared or supported accommodation?*
- *What plans, if any, are in place for the person with disability when the parent is unable to continue to provide support in the home due to illness or death?*

## **Conclusion to the chapter**

This chapter has introduced the research thesis, and by providing a brief history of accommodation services for people with intellectual disability living in Western Australia (WA), has ‘set the scene’ for the literature review. It is also pertinent to this study that the reader understands the complex and changing landscape of disability services over the last few decades nationally and in WA, and the implications of the introduction of the National Disability Insurance Scheme (NDIS). While the full extent of the impact of the NDIS on disability services in WA will not be known for some years, it is important to include progress prior to completion of the thesis in order to gain an insight into the impact on future accommodation funding and options.

The need for a greater understanding of the experiences of ageing parent carers grew from my personal experience of employment in the disability sector, and led me to the development of this research study. The significance of the study and statement of purpose assisted with the formation of the research questions and sub-questions that outline the approach to the interviews that were conducted.

## **Chapter 2      Review of the literature**

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To gain an understanding of previous research and published literature relating to ageing parent carers with a son or daughter with intellectual disability living at home with them, I searched databases with key search terms “ageing parent carers”, “intellectual disability”, “accommodation”, and “planning”. Initially I didn’t place date or location restrictions on the literature search. To narrow the literature to the most relevant, I selected Australian literature and literature from countries with societal, economic and demographic similarities where possible, such as the United Kingdom, Canada and the United States. Both peer-reviewed journal articles and published books were reviewed.

The review of the literature revealed four key themes that may impact on decisions and choices families make in regards to accommodation options for their adult child with disability. These include,

- deinstitutionalisation and accommodation options for people with disability and their families,
- perceived barriers to seeking accommodation,
- health and wellbeing of the parents or family carers providing extended caregiving, and moving from home,
- planning for the future, knowledge and available resources.

Further analysis revealed common areas of discussion bracketed within the four key themes with many overlapping into another key theme.

### **2.1 Impact of deinstitutionalisation and accommodation choices**

Until the early 1970s in Australia, the options for accommodation for people with disability was largely limited to institutions (Chenoweth, 1999). Since then, paradigm shifts for people with disability have included the integration into mainstream sport and leisure, open and supported employment options, inclusive education settings, as well as the move to accommodation in a community setting (Chenoweth, 1999). The principle of normalisation and social role valorisation led a new movement in disability policies and services since the 1960s, promoting socially valued roles in society for people with disability (Wolfensberger, 1983). This led to deinstitutionalisation and the move for

people with disability to live in community settings in regular housing, to enable them to experience life similar to the ways of mainstream society.

However, Chenoweth (1999) highlights the negative impact of this movement for some people with disability, such as homelessness and a documented rise in the number of people with intellectual disability in the justice system. In addition, Chenoweth presents the criticism that smaller community accommodation options, such as group homes, are a representation of larger institutions on a smaller scale, and “community living has meant more staff moving through and around people with disabilities than before” (Chenoweth, 1999, p. 86). This opinion is supported by Barnes and Mercer (2003) who state that “day centres and small group homes or hostels in the community still demonstrated an institutional atmosphere” (p. 38).

During the closure of institutions in Australia during the 1990s, some families opposed the idea of the relocation of their relatives with disability into community based housing options (Wiesel & Bigby, 2015). Such opposition was responsible for group homes and shared living arrangements, the retention of some institutions with improvements that embodied normalisation ideology, and even the retention of some institutions themselves (Wiesel & Bigby, 2015). Wiesel and Bigby (2015) identified that deinstitutionalisation has impacted on broader social and urban issues, such as an increase in homelessness of people with intellectual disability due to a shortfall of affordable and appropriate accommodation, and urban renewal projects that affect the “social mix of urban areas” (p. 15). Deinstitutionalisation may even have contributed to the pressure that families felt to continue to provide accommodation in the family home for their adult child with intellectual disability (Gilbert, Lankshear, & Petersen, 2008).

### ***Community participation and integration***

Another criticism of deinstitutionalisation has been lack of focus on community participation for people with disability moving into the community; a physical presence, not a participatory one. Chenoweth (1999) presents the opinions of several authors (O’Brien, 1987; Lord & Pedlar, 1991; Parmenter, 1994) who support this view, highlighting the difference between successful physical integration into a community, and true participation in community life. Hutchison (cited in Chenoweth, 1999) describes two broad approaches to deinstitutionalisation policy; a social planning approach which focuses on the removal of people from institutions with little concern

for quality of life, and the community development approach which centres on building the capacity of the community and community inclusion for people with disability.

The *Shut Out* report, released in 2009, also questioned the success of deinstitutionalisation.

Many of the large institutions that housed generations of people with disabilities—out of sight and out of mind—are now closed. Australians with disabilities are now largely free to live in the community. Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard (Commonwealth of Australia, 2009, p. 1)

Since the 1960s, the progress of deinstitutionalisation has not always followed a positive trajectory. Wiesel and Bigby (2015, p. 6) described the progress of deinstitutionalisation in Australia as starting with the “downsizing of institutions and piecemeal relocation of residents” from institutions during the 1960s and 1970s (Neilson Associates cited in Wiesel & Bigby, 2015, p. 6) to the community participation objective as a result of the *Disability Services Act 1986*, to more recently being largely ignored in the *National Disability Strategy (NDS)* released in 2010, where deinstitutionalisation was considered as being a completed project and “a thing of the past”.

Ward (2011) ascertains that in the United Kingdom, even though the ‘voices’ of people with disability are now heard in regards to policy development since deinstitutionalisation, “they continue to be marginalised within the realms of civil society” (p. 169). Chenoweth (1999) questions whether communities are supportive of people with disability, and if they are prepared to welcome people living with disability within their community. Economics has played a role in the “neglect of community participation”, favouring the need to place people into community based housing and closing the institutions, above the “deeper issues such as quality of life in the

community” (Chenoweth, 1999, p. 87). In a study based in the United Kingdom (UK), Emerson (2004) suggests that deinstitutionalisation and the move to more community based housing has only moderately contributed to an improved quality of life for people with intellectual disability, specifically in regards to social inclusivity, choice and control of major life decisions, and health status.

### ***Slipping through the gaps***

While the emphasis has been on deinstitutionalisation, little attention has been paid to planning the future accommodation needs of people with intellectual disability who were still living in the family home (Prosser, 1997). A principle of deinstitutionalisation was for people with disability to have the opportunity to access a range of accommodation options of their choice. Shaw, Cartwright, and Craig (2011) argue that people with intellectual disability may not have that choice and live in the family home relying on family members and other informal carers to provide the support they need. The Australian research revealed that parents were not offered alternatives to informal care, therefore their child remained living at home into adulthood, and it was only when the parents themselves were ageing that they were forced to consider alternative accommodation for them (Shaw et al., 2011). When caring at home was the only means of family support, some families may even consider that institutionalisation was the only other option, therefore “their care has remained a private concern, seen essentially as a family responsibility” (Knox & Bigby, 2007, p. 288). The result may be that these families are ‘slipping through the gaps’ of service provision, and the measure of unmet need for disability accommodation is unreliable. Furthermore, the unique features of an ageing parent carer/adult child dependent relationship may mean that older parent carers may also ‘slip through the gaps’ when it comes to service provision as “they do not fit neatly into either ageing or disability service systems” (Bigby, 2004, p. 196).

## **2.2 Perceived barriers to seeking accommodation**

Previous studies identified barriers, or perceived barriers, to accessing accommodation and planning for future accommodation for the participants’ adult child with intellectual disability. Older carers may feel that accepting any assistance with accommodation for their adult child with disability may indicate the inability to cope, and a failing in their caring role (Prosser, 1997). Bibby’s 2012 review of UK literature identified that carers

felt a ‘sense of duty’ which may influence decisions regarding future care (Bibby, 2012). In Australia the SDAC (2012) also reported that primary carers cited a “sense of family responsibility” and “feeling of emotional obligation” as the main reasons they took on the role of primary carer (Australian Bureau of Statistics, 2012a).

### ***Reciprocal care relationship***

One of the benefits of continuing to have a son or daughter with intellectual disability living in the family home may be the provision of reciprocal caregiving (Heller & Caldwell, 2006; Prosser, 1997). As parents age and the caring relationship becomes reciprocal, it is harder to differentiate between “the carer and the cared for” (Ward, 2011, p. 171). Cuskelly (2006) agrees that the benefits of continuing to live with an adult child with disability may be mutual, and companionship, emotional and practical supports are amongst the positive experiences. Providing care into older age may not be seen as a burden. The interdependent relationship, mutual care and companionship that continued care may provide, could override any ideology of ‘burden’ (Williams & Robinson, 2001).

It is also possible that many families may not accept the title of ‘carer’ and believe that providing ongoing support for a family member in their role as a parent is a mutual relationship (Knox & Bigby, 2007). Furthermore, Ward (2016) suggests that there is little recognition of the caring role that people with disability play in the lives of others, as they are essentially seen as ‘service users’ (p. 171). Williams and Robinson (2001) suggest that reciprocal caregiving needs to be recognised and acknowledged as a caring relationship, “rather than categorization of people as carers and cared for” (p. 61). In addition, the needs of both the parent and adult child need to be considered together, as the lack of recognition of the reciprocal relationship and the characteristic of interchanging roles may also be a barrier to planning for the future (Bowey & McGlaughlin, 2007). Ward (2011) identified that while there has been some policy development and research supporting the needs of the family carer, there has been little recognition of the needs of the person with disability who also provides care. Previous research has revealed the importance of the value that the people with disability placed on being able to help others at home and in the community, and the value of learning of new skills to develop independence (Barr, McConkey, & McConaghie, 2003).



The reciprocal relationship may also be considered from a financial viewpoint. The financial contribution to the family income from the person with disability may be required to maintain viability of the household (Bigby, 2004). Walker and Walker (cited in Dillenburg & McKerr, 2011) also concluded that reluctance to seek out of home support may be due to the interdependent financial relationship.

### ***Perceived quality of care and dissatisfaction with accommodation services***

A barrier to seeking out of home care identified in the literature is the suggestion that families may have concerns over the quality of care that their adult child may receive in residential accommodation (Prosser, 1997; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). In research conducted in the UK, Davys and Haigh (2008) found that the greatest barrier to seeking out of home care is a dissatisfaction with available services.

Dissatisfaction incorporates a number of elements and includes anger at service providers, a sense of having to fight to get what you want, distrust of services, a sense of parents and service providers being on opposing sides and a feeling that services provided are not what parents want and lack quality (Davys & Haigh, 2008, p. 68).

In addition, there may be concern for the health of the adult child with disability and apprehension that supported accommodation may not provide appropriate or adequate care. Shaw et al. (2011) reported that more than 40% of parents who participated in their Australian study expressed that they would like to have their adult child living in supported accommodation, but due to their “concerns regarding the health and well-being of their child, they were obliged to continue to care for them” (p. 898).

Research conducted in Victoria, Australia, questioned the difficulty in defining what constitutes good accommodation for people with disability, specifically for those with a more severe disability (Bigby, Knox, Beadle-Brown, & Bould, 2014). The study examined the quality of life for the residents of group homes, using a quality of life scale, and the influence that organisational factors have on staff practices within group homes. Bigby et al. (2014) concluded that observation of staff practices to improve the quality of services provided in group homes is required to ensure that residents “are to experience the type of improved quality of life foreshadowed in the recent Australian disability reforms” (pg. 364).

Previous research found that for many ageing parents in the caring role, mistrust in the system due to previous experiences is an issue that creates a barrier when planning for and seeking accommodation for their adult child with disability (Cuskelly, 2006; Heller & Caldwell, 2006; Prosser, 1997). Knox and Bigby (2007) agree and state that due to past experiences with formal services, and the “historical context of service ideologies”, older family carers are less likely to seek formal service access than their younger counterparts (p. 288). The cohort of parents born before deinstitutionalisation have been witness to a dramatic change in society’s treatment and attitude towards people with disability, and have seen striking changes in governmental policies (Bigby, 2004). Past attitudes and experiences with residential services may continue to remain a barrier for these families.

Trust that someone else can provide adequate care may play an even greater role when ageing caregivers had not had previous access to support services (Heller & Caldwell, 2006). In the Australian research conducted by Franz et al. (2014), ageing parents revealed that the lack of support services in place when their child was younger influenced their decisions to continue to provide care in the family home as they aged, but noted that these families also responded positively to new services and supports that enabled a more inclusive life. Some ageing caregivers may also feel a sense of distrust with the service providers and health professionals themselves. Bigby (2004) states that parents may feel that professionals show a disregard of the “knowledge and expertise of the parents about their own child” and may have felt devalued in their caring role (p. 196).

### ***Current or previous access to respite care***

The past use of respite care may also impact on the decisions family carers make when deciding on future permanent accommodation. Gilbert et al. (2008) suggest that negative experiences of respite care may have contributed to reluctance to explore residential options of accommodation. Using respite services may also contribute to carer stress and result in feelings of guilt, and deprive the parent carer/s of the satisfaction of sharing the day-to-day life of their adult child (Bigby, 2004).

However, not all studies reviewed in the literature agreed that the use of respite services were negative, or acted as a deterrent to accessing permanent accommodation. McConkey, Kelly, Mannan, and Craig (2011) claimed that following their research in

Ireland, participants were found to have been twice as likely to have moved from living in the family home to residential or supported accommodation when they had accessed respite services previously. Shaw et al. (2011) support this and state that the regular use of respite services may improve the development of independent living skills and provide the experience that may assist the transition to permanent accommodation. Furthermore, access to respite not only provides parents with a break from the caring role, but may act to increase the recreational participation for the adult child with disability (Bigby, 2004).

The severity of the disability and the impact that challenging behaviours or high level of personal care has on the likelihood that a family will seek respite services is largely unexplored in the literature. However, as a result of the findings in the SDAC (2009), Qu et al. (2012) concluded that people with a milder disability were more likely to be in an older age bracket while still being cared for at home by an ageing parent. McConkey et al. (2011) suggest that a person with a lower level of disability is more likely to remain at home due to the fewer demands on the family caregiver, which could be an explanation for the results in the SDAC (2009).

### ***Physical barriers – the built environment***

The lack of appropriate housing stock available was another common barrier in the literature that families reported when seeking accommodation for their adult child with disability (Cuskelly, 2006; Grey, Griffith, Totsika, & Hastings, 2015; Shaw et al., 2011; Stancliffe, 2014). In the 2014 report presented to the Legislative Assembly in WA *Client driven? Or driven to despair?* it was reported that the issue of appropriate housing stock is not a new one, and that a “significant shortfall existed in WA in relation to accommodation and other support services for people with moderate, severe and profound disabilities” (Community Development and Justice Standing Committee, 2014).

On a national level, Stancliffe (2014) reported that many people with disability are remaining in the family home being cared for by ageing parents due to the shortage of accommodation services. The shortage of suitable accommodation may place increasing stress on both families and disability services, and increase the chances that people with disability only gain access to out-of-home accommodation at a time of crisis (Stancliffe, 2014).

To address the lack of appropriate housing stock, one solution may be the provision of suitable private housing. However, Franz et al. (2014) identified that the private housing market did not make allowances for suitable housing for people with disability, including location and the design. Accessibility does not only refer to wheelchair accessibility. Disabilities such as vision impairment and intellectual disability may necessitate specific design requirements, and design needs to be mindful of the long term adaptability and the unique experiences of ageing with disability (Franz et al., 2014).

However, if families do not have the financial means to fund private housing or private rental, funding can be a further barrier that restricts a person with disability making the move to out-of-home living. In 2014, of the 679 applications made to the DSC for funding for accommodation support, only 68 were granted (Community Development and Justice Standing Committee, 2014). The non-existence of a wait list for accommodation funding could make future planning impossible for families. In recognition of this barrier, recommendations were made to the WA Legislative Assembly to consider the options of a wait list, making it dependent on how long a person had been waiting for accommodation funding, and the age of the carer (Community Development and Justice Standing Committee, 2014, p. 39). Funding is discussed further in Chapter 2.3.

### ***Cultural or values based influences***

Cultural, religious or values based beliefs may also affect the decision continue in the caring role. While not all members of a cultural group may have the same opinions in regards to providing care and family 'duty', it should be acknowledged that some cultural groups may have a feeling of shame, and choose to 'hide' a family member with disability (Cuskelly, 2006). Prosser (1997) suggests that the delayed decisions regarding future care for their adult child with disability may be influenced by family cultural norms and the 'role of kin'. Obligatory traditional roles of caring for one's own, and the concept of 'the best care possible' may also be an influence when ageing parent carers continue in the caregiving role (Prosser, 1997).

Within the Australian Indigenous population the prevalence of disability is approximately twice that of the rest of the population, however these statistics are unclear due to the culture of Indigenous peoples' reluctance to identify as having

disability (Aboriginal Disability Network NSW, 2007). At the time of their research the Aboriginal Disability Network NSW (2007) reported that very few Aboriginal people access formal services and their needs are largely unmet. It was concluded that most of the supports provided to Indigenous people with disability are provided by families or through kinship networks.

It is a situation that is distressing and inexplicable in a country that in many other facets of disability rights is regarded as a world leader (Aboriginal Disability Network NSW, 2007, p. 3).

In addition, current supported accommodation options have issues that would need to be addressed to allow greater access for Indigenous people with disability. These include: risk of cultural isolation and staff who lack knowledge of Aboriginal cultural issues; long distances from Aboriginal communities to supported accommodation options means that families are unable to visit regularly; fear of government provided accommodation stemming from historical contexts; and architectural design that does not meet cultural needs (Aboriginal Disability Network NSW, 2007).

The moral duty of care that many families experience may be influenced by religious beliefs. Buhai (2007) states that Christianity teaches moral obligations of families to care for their children, and God created all, including those with disability. This sense of duty of care “to act morally encourages, if not requires, that Christian parents support their adult disabled children indefinitely” (Buhai, 2007, p. 740). In the Jewish faith it is a man’s obligation to support his wife (or ex-wife), and continued support for children, especially minors or those unable to care for themselves, is an indirect responsibility (Buhai, 2007). Furthermore, Jewish law presumes the lifelong responsibility of a mother towards her children, and parental care will continue until a child has the ability to care for themselves, especially if the parents have the financial ability to continue to provide care (Buhai, 2007).

While both Christianity and Judaism do not expressly demand that parents care for their disabled child, Islamic law is very clear about the obligations to care for adult children with disability. Under Islamic law, all children, male or female, are entitled to ongoing care regardless of the disability (Buhai, 2007). Buhai (2007) acknowledges that not all religions explicitly address the duty of parental care, however moral beliefs and values

that religions teach “tend to support a moral obligation for parents to care for their adult disabled children indefinitely” (p. 743).

Philosophical theories of morality and human ethics may also have a place in decisions families make to continue to care for their adult child with disability at home. Buhai (2007) explored the moral theory of deontology, virtue ethics and utilitarianism, and how they influence the ongoing parental care of an adult child with disability.

Immanuel Kant (1724-1804), a notable author of deontological moral theory, believed that basic rights, respect and freedom of humanity dictates that parents should care for their adult child with disability because it is morally the right thing to do (Buhai, 2007). Buhai (2007) claimed that virtue ethics, based upon the writings of Aristotle, places “emphasis on the virtues of the individual” would likely support a moral obligation of parents to provide care to an adult child with disability (p. 745-746). Similarly, Buhai (2007) states that utilitarian theory would support parents provision of care to their children as they are in the best position to do this, and children benefit most from care by their parents.

## **2.3 Impact of life long caring on the carers and cared for**

As a parent ages, the caring role may become more difficult due to health issues of the carer, the physical height and weight of their adult child they are caring for, or their increased behaviours of concern (Grey et al., 2015). In addition, Grey et al. (2015) found that parent carers felt that the caring role had an effect on the relationships with other members of the family, and the impact of lifelong caring for an adult child with disability was felt by the entire family. Friction between siblings, and the increased dependence on parental carers may also lead to a negative impact on the family, and the loss of quality of life of the carer (Eley, Boyes, Young, & Hegney, 2009). Tabatabainia (2003) states that the effects on the family and the family carer, such as impact on social lives, personal lives, leisure time and time for other children or family members, influenced whether some families opposed deinstitutionalisation. Some families in the study by Tabatabainia (2003) were also aware that caring for a family member at home meant that they received little or no community support in their caring role.

While older parents may not share the same sentiment toward their caring role, dependent on their satisfaction and benefits gained in their parenting role and their past experiences with services (Bigby, 2004), there is no doubt that caring into older age has

an impact on the lifestyle of a carer. The nature of being an ageing carer of an adult child with disability means that many ageing carers may not experience role reversal as they age, so effectively the caring process ends in the carers death or ill health, not the death or ill health of the ‘cared for’ (Bigby, 2004). Qu et al. (2012) stated that ageing parent carers are providing “an important service to the community that saves a huge amount of public resources”, and that this contribution, often lasting the lifetime of the parent, should be recognised with better support and services (p. 13).

### ***Financial impact on the family income***

Providing care in the family home also impacts on the employment and financial status of the parent carer. Participation in the paid workforce is reduced for those who provide care in the home, which can affect the financial stability now and for the future (Qu et al., 2012). Qu et al. (2012) highlighted the financial impact that caring in the family home has on mother carers in particular when planning for their own retirement, as more than half of the mother carers over the age of 65 years were sole parents, which left them particularly disadvantaged. The financial disadvantage also impacts on the ability for these families to seek alternative housing, which leaves them reliant on government funding to allow them to move out of home.

The Combined Application Process (CAP) is the funding stream for people living with disability in WA seeking funding for shared supported accommodation (group homes), supported individual community living, or for increased support in the home usually by a support worker (Community Development and Justice Standing Committee, 2014). Evidence suggests that this funding is not sufficient for the many people requesting support every year in WA. In the report to the WA Legislative Assembly into funding for people with disability -

According to the DSC, the average waiting period between an initial CAP application and funding being received is two years. However, evidence submitted to the Committee indicates that applicants may wait five or six years and even up to nine years (Community Development and Justice Standing Committee, 2014, pp. 10-11).

The purpose of the CAP assessments is to ensure that people who are in most urgent need of funding receive the funding they require. However, due to the extensive wait for funding approval (either perceived or real) families often ‘exaggerate’ the urgency

of their need to ensure they are in receipt of funding (Community Development and Justice Standing Committee, 2014). According to the report, until the full implementation of the NDIS in WA this funding process will remain in place, which may be daunting for the many families who have applied and may have already been waiting for funding for several years.

### ***Effect on carer health***

Consequences of lifelong caring for many may result in stress, and have a psychological and physical impact on the carer (Cuskelly, 2006; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014). Cuskelly (2006) expanded on this, and stated that social isolation due to the caring role and its impact on employment options, may also contribute to depression, a strained relationship with their child, and “guilt in response to feeling angry or burdened” (p. 22). Research conducted in Northern Ireland by Taggart et al. (2012) found that a large proportion of the parent carers in their study attributed anxiety and depression to their role as a caregiver as they aged, in addition to physical health issues, such as back problems and painful joints. Health issues as a result of the ageing process may further contribute to associated depression.

However, Seltzer and Krauss (cited in Bigby, 2004, p. 198) argued that older carers are more resilient than younger caregivers, and “older mothers of adults with an intellectual disability experience less depression and have greater subjective well-being” than other women similar in age. In addition, the involvement of siblings in the life of their brother or sister with disability may also impact on the wellbeing of the older parent carer.

Due to the diminishing sources of support related to ageing, such as the death or ageing of a spouse or friends, not only is an ageing parent carer faced with the stresses related to their own health, financial status and social isolation, their greatest anxiety relates to the future care of their adult child with disability (Bigby, 2004). Stancliffe (2014) agrees and states that as the social participation of the ageing parent carer diminishes, so too will the social participation of the person with the disability, leading to “social isolation and severe family stress” (p. 1061).



### ***Impact of moving from home and relinquishing parental care***

Moving from home to more independent living in the community may impact a person with disability both emotionally and physically, regardless of the reason that necessitated the move. This may include the loss of contact of people that previously played a role in their lives, disconnection from the community they previously lived in, and even a loss of independence out of the family home (Barr et al., 2003). If the move was sudden, the impact may be even greater, and affect quality of life, impacting on physical and mental health.

The impact that the death of a parent has on the life of an adult child with disability who has remained living in the family home is a practical one, but is also often the loss of the advocate role that a parent plays, social contacts and companionship (Bigby, 2004). However, Bigby highlights that if a reciprocal caregiving relationship was present, the responsibility of providing care would no longer be relevant for the person with disability, and the move to shared accommodation may open new opportunities for the development of informal networks.

The planning of and actual physical move, from home accommodation to independent or supported accommodation for their son or daughter with disability, may impact on the parents in several ways. If the parents are aged in their fifties or sixties, there are many external factors of change that may already be in place in their lives, such as retirement, health status, and even social change due to loss of friends or family as they age (Bigby, 2004). In addition, the difficulty in making plans for accommodation for the remainder of their son or daughter's life and "the risk of locking someone into an environment which may become inappropriate or more restrictive than warranted" may be an additional cause of stress (Bigby, 2004, p. 207).

### ***Independence and skill development***

Skill development to enable independent living may not have been a priority for people with intellectual disability who have remained living at home throughout their lives. Some parents, when planning the future for their adult child with intellectual disability, place a greater value on security as opposed to developing skills for independence.

Instead of looking towards increased independence for their adult child in the future, parents seek residential accommodation to duplicate the care and protection they have provided at home (Bigby, 2004, p. 205).

Shaw et al. (2011) stated that parents expressed concerns that their adult child “had not acquired the skills necessary to maximise their functional independence” and they doubted that basic independence skills could be learnt in older adulthood (p. 901).

Nevertheless, Tabatabainia (2003) suggests that while living at home with family carers may restrict the social life and leisure activities for young people with disability, finding alternative accommodation may assist them to be more independent. An example of this was present in the study by Isaacson, Cocks, and Netto (2014), where the process of development of independence was a gradual one following the move to individual supported living (ISL) for two young men with intellectual disability in WA. Both young men viewed themselves as adults, however Isaacson et al. (2014) suggested that “parent uncertainty about the roles and abilities of their sons contributed to the difficulties they had in letting go of parenting roles” (p. 278).

Individual supported living (ISL) is a contemporary model of accommodation that focusses on a “single person with a disability using person-centred principles” to seek living arrangements (Cocks et al., 2014, p. 614). Instead of ‘placing people’ in accommodation, ISL takes into consideration the person’s preferences, relationships with others and personal choices, and does not require a ‘minimum level of skill development’ (Cocks et al., 2014). Cocks et al. state that the ideology of ISL is to “ensure that there are sufficient flexible supports, continuous planning, and contingency plans to enable anyone to have their own home” (p. 620). Bigby (2004) also identified that rights based decisions by older family carers was often in conflict with the rights of the person with the disability. This included the continuance of the current living situation of interdependence and reciprocity, and reluctance to engage with formal services, in preference to rights of independence. Older parents may also have a different view of what the future care will look like, and this in itself may be in conflict with service providers (Bigby, 2004). The contemporary model of ISL may not even be considered by ageing parent carers when planning for the future accommodation for their adult child with intellectual disability.

## 2.4 Planning for the future

One of the themes identified in the review of the literature was the planning undertaken, or lack of planning undertaken, for the future care of an adult child with intellectual disability when the parent or primary caregiver are no longer able to provide care.

Bibby (2012) reported on key findings from previous UK research and literature (spanning a 20 year period) that explored reasons why ageing parents and carers were reluctant to undertake planning for future care for their son or daughter with a learning disability. Among the barriers that Bibby identified, a lack of confidence in formal service provision and health professionals was a recurring theme, and a major barrier to the planning process.

In their research conducted in the United States, Heller and Caldwell (2006) identified several obstacles to adequate planning, including the lack of and availability of information and appropriate services. Bigby (2004) also reported previous research had found that a lack of knowledge of options available for accommodation was a barrier to planning. Appropriate education and information regarding services, planning and support options, and assistance to navigate services are strategies to inform older parent caregivers about the options available for the future planning for their adult child with disability (Bigby, 2004). However, the provision of legal information and assistance with planning will not always ensure that planning processes will be undertaken by families (Heller & Caldwell, 2006). Prosser (1997) suggests that an influence on the planning process for some families involves not only the access to resources, but also family attitudes to obligations and responsibilities to care for their adult child with intellectual disability.

### *Why is planning so important and what will it achieve?*

Plans have two major functions: facilitating the transition from parental care; and ensuring in the longer term an optimum quality of life and security for an ageing adult with an intellectual disability (Bigby, 2004, p. 204).

Bigby (1996) sought to investigate the planning that parents had undertaken for their adult child with disability who had remained living at home with them until middle-age, and concluded that most of the parents in the Australian study had made some form of plan for the future. Four types of plans were identified that had been either put in place or implied; explicit key succession plans, implicit key succession plans, financial plans

and residential plans. Where explicit plans had been made, over 80% nominated siblings as the key person to either oversee care or financial management. Where implicit plans were in place, often this was the only plan made, and was generally ‘agreed to’ as an expectation. A plan for a key support person to oversee future support and services had been more successful and effective than plans that had been set in place just prior to the loss of the parent who provided the care. Planning for future accommodation options by a key support person allows for flexibility, contemporary or new opportunities, and doesn’t “tie adults with intellectual disability into the particular visions of their parents and earlier times” (Bigby, 2004, p. 207).

Heller and Caldwell (2006) identified that previous research had indicated that while some families had made plans, most of these plans were financial or legal in nature, and less than half of families make plans for future living arrangements. Prosser (1997) reported that this figure could be as low as 28% of carers who had made any residential plans for future care, and even less where the carers were aged over 65 years. Prosser’s UK research also revealed that when the primary carer was a parent, less than 20% had made any plans for the future, and would not plan for any future living arrangements until they were no longer able to provide the care.

Franz et al. (2014) recognised the importance of planning and the complex nature of individualised planning for families and people with disability:

‘Futures planning’ is widely recognised as important to ensure continued support and financial stability for people with disabilities who require care. Long-term plans for housing may mean, for example, a change in housing situation, putting arrangements in place for a future move or future home modifications, or legal and financial arrangements for continued ownership or occupancy (Franz et al., 2014, p. 33).

The access to appropriate information, especially in regards to legal and financial planning, needs to take into consideration impact on government benefits, legal guardianship, and setting up trust funds if applicable (Prosser, 1997). An example of this type of planning assistance is evident in the operation of the Future Living Trust, a not for profit charitable organisation operating in Perth, originating from the Activ Foundation in the late 1980s (Future Living Trust, 2015). The Trust works with families to assist them in the planning process in response to the question raised by

parents “*Who will look out for our child when we are no longer able to?*” (Future Living Trust, 2015, p. 2). Financial support for the Trust is drawn from donations, bequests, grants, fundraising and the provision of services, and in turn manages monies in trust for individuals securing the future of their own son or daughter.

### ***Facing mortality***

The emotional and confrontational nature of making plans for a loved one when you are no longer able to care for them yourself may also be a deterrent to actually making any plans at all (Bigby, 1996; Grey et al., 2015; Heller & Caldwell, 2006). Planning for future residential care forces caregivers to face the reality of their own mortality (Heller & Caldwell, 2006). Prosser (1997) agrees, stating that previous studies had reported that elderly carers find the subject of future accommodation plans “too painful to broach and do not make any concrete plans until it becomes unavoidable” (p. 17).

Bowey and McGlaughlin (2007) found that feelings of guilt about no longer being able to provide care, and a difficulty in relinquishing the role of carer, also may contribute to the stress and anguish felt by ageing parent carers when considering accommodation options for their adult child. Their UK based research revealed that many of the participants were very concerned about the future, and had been for most of their lives, expressed by one parent that “she might prefer her son to die before she does” (Bowey & McGlaughlin, 2007, p. 44).

### ***The roles of siblings or relatives***

The existence of informal support in the home also affects the likelihood that out of home support may be sought. Research has found that when parent carers have had support from other family members or friends they are less likely to have made plans for the future, possibly due to the carer burden being reduced, or possibly due to the assumption on behalf of the parent carer that the supportive family or friends may take over the caring role in the future (Bowey & McGlaughlin, 2007). This was a common theme in the literature; in many instances it is assumed that once the parents can no longer provide care it will become the role of another family member or sibling, however often the relative or sibling was not involved in the planning process for this (Bigby, 1996; Heller & Caldwell, 2006; Taggart et al., 2012). Taggart et al. (2012) reported that over half of the participants in their research felt that it was acceptable that the siblings take on the caring role when their parents are no longer able to. However,

Gilbert et al. (2008) disagree, stating that most parents in their research “did not want their other children to take on the physical responsibility for caring for their sibling”, but suggested that they may become advocates for them (p. 59). Davys and Haigh (2008) supported this, with respondents in their research claiming that their other children need to have “lives of their own”, but still expected that they would want ongoing involvement with their sibling after their parents were gone (p. 68). The changes in contemporary family life, such as smaller families, extended families with diverse relationships, and expectations of women in the workforce may also affect the capacity for other family members or siblings to provide care (Cuskelly, 2006).

The suggestion of a key person as a part of the informal network could often be a sibling, but not always the sibling closest in age (Bigby, 2004). However, if the key person was the same age or older than the person with the disability, they may even predecease them, which could leave them in a vulnerable position with no informal support, and reliant on formal support services (Bigby, 2004). Seltzer et al. (cited in Bigby, 2004) found that while siblings often had meaningful relationships with their brother or sister with intellectual disability, the relationship was often only an emotional one, not a practical one.

## **Conclusion to the chapter**

The review of the literature revealed similar key themes regarding the reasons why many families choose to continue to care for their adult child with intellectual disability at home, why they don’t plan for care and accommodation for when they are no longer able to provide care themselves, the real or perceived barriers to this planning, and the impact that the lifelong caring role has had on their lives and the lives of their family members. A search of the literature failed to find similar studies previously conducted in urban Perth, though there are significant studies in Victoria (Bigby, 1996; Bigby et al., 2011; Knox & Bigby, 2007) relating to ageing parents caring for an adult child with disability, and accommodation options for them. Chapter 3 introduces the theoretical framework, methodology, and methods selected, and the data analysis approach utilised in this study.

## **Chapter 3      Research design**

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This chapter will describe and justify the research design for this study by outlining the theoretical and methodological framework that was utilised, and the steps taken to develop the research design. The method used, sampling strategy, eligibility criteria and recruitment methods are presented. The chapter also considers the data analysis procedure and the use of computer software to assist in the analysis process, ethics and risk assessments conducted prior to the study, and the consideration of validity and reliability appropriate for this type of qualitative research.

### **3.1 Theoretical and methodological framework**

The research study was developed from the philosophical assumption that there are multiple realities in the experiences of families living with a child with intellectual disability. Described by Creswell (2013) as an ontological assumption, it refers to the “nature of reality and its characteristics”(p. 13). Crotty (1998) describes ontology as “the study of being” which assists us to understand “what is”, however he sees ontology as terminology that is often misused, and essentially the use of “theoretical framework” is more preferable (pp. 10-11).

The theoretical framework for this study is formed through a philosophical worldview assumption. Social constructivism, a worldview described by Creswell (2013), is an assumption that asserts that an individual’s world and their subjective meanings people ascribe to their experience are strongly shaped by dominant shared cultural values. Constructivism also draws from historical perspectives of the individuals, social meaning and interaction within communities (Crotty, 1998). Since the late 1960s, dominant interpretations of the lives of people with disability changed from a medical or biological paradigm, to one from a sociocultural perspective. With the emergence of normalisation theory, or ‘social role valorisation’, introduced by Wolf Wolfensberger in 1972, the terminology the ‘social model of disability’ began to be used (Sullivan, 2009).

The social model of disability provides the theoretical framework used for this study. This study explores the lived experiences of families to understand decisions they have made as their child with intellectual disability has grown into adulthood, and the reasons behind the decisions regarding future accommodation and care for them. A ‘disability

interpretive lens' aids in the understanding and interpretation of disability as a 'difference', not as a 'defect', which allows the research to focus on the differences in the lives of people with disability, and not the societal responses to people with disability (Creswell, 2013).

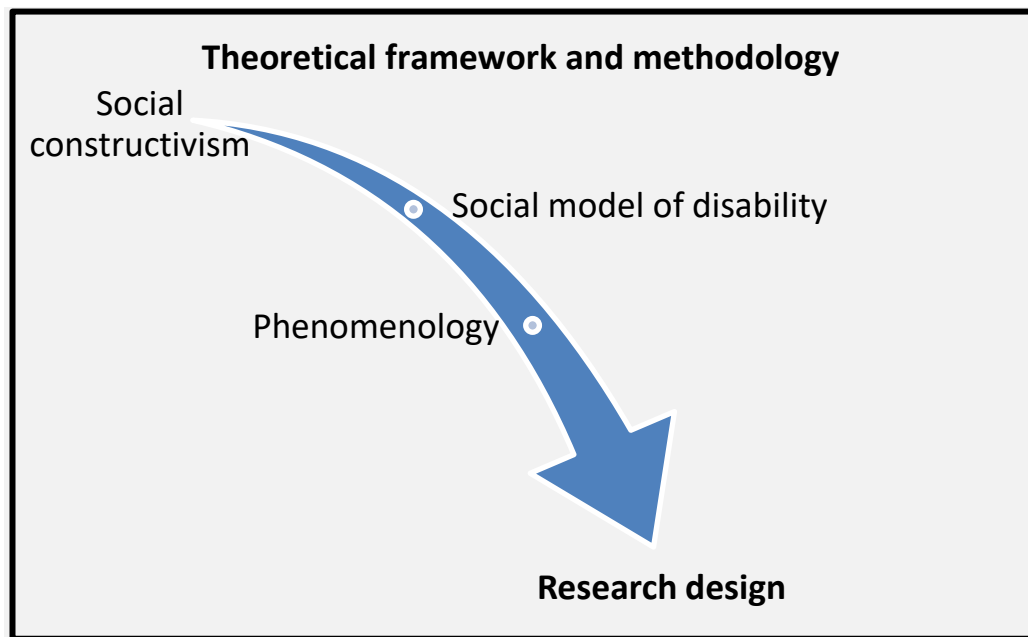
A phenomenological approach was chosen, essentially searching for a common meaning or 'essence' that the participants experienced (the phenomenon in this study is the lived experiences described above), and then describing what, and how, they experienced it (Creswell, 2013). Moustakas (1994) explains that phenomenology seeks meanings of and descriptions of experiences, and reflects on these experiences to assist us gain a greater understanding of phenomenon. **Figure 1** is a visual representation of the process of building the design of this study.

A phenomenological approach to human science research, originally pioneered by Husserl (1859-1938), is characterised by methods that gain an understanding of the meaning people make of their experiences, and an insight, into the lives and experiences of others. Husserl proposed that researchers were required to 'put aside' or 'bracket' their own experiences, personal beliefs or bias, so that the research can be approached without prejudice (Corby, Taggart, & Cousins, 2015). This bracketing is to ensure that each unique experience is described and presented, and the meanings of those who experience the phenomenon are not influenced by the researcher's preconceptions.

One of the characteristics of phenomenological research writing is analysis into themes, and usually includes verbatim quotes from the participants themselves (Corby et al., 2015). The themes are then categorised into 'structural' and 'textural' descriptions of the phenomenon experienced. The structural description is the circumstances that influence how the phenomenon is experienced, and the textural description is what they experienced (Creswell, 2013). This results in the researcher being able to write a description that reveals the 'essence' of the phenomenon, the experiences that the participants have in common, expressed by Polkinghorne (1989) as "I understand better what it is like for someone to experience that" (cited in Creswell, 2013, p. 82).



**Figure 1:** Building the design of the research



### **3.2 Method and sampling**

A purposive criterion sampling approach was utilised in this study, selecting participants who as ageing parent carers have experienced life in a caring role for an adult child with intellectual disability. Purposive criterion sampling enables the researcher to select “information rich cases” to enable an insight into the phenomenon that adds credibility to the research (Emmel et al., 2013, pp. 36-37). This sampling strategy relies on the participants to have all experienced the phenomenon (Creswell, 2013). In addition, ‘single-contact’ interviews conducted in the homes of the parent carers, as suggested by Gilbert et al. (2008), was the most appropriate way to conduct the interviews and enables clear explanations of the nature of the research and the reason for the data collection.

The sample frame for this study includes geographical location and the age of the parent/s providing care. All participants needed to be currently caring for their adult child with intellectual disability at home. Participants were not considered eligible if their experience was retrospective (their adult child had already left home). The reason for excluding retrospective experiences was to enhance the validity of the research and to ensure that participants recall and the outcomes of their experiences did not influence their responses to the interview questions (Cox & Hassard, 2007).

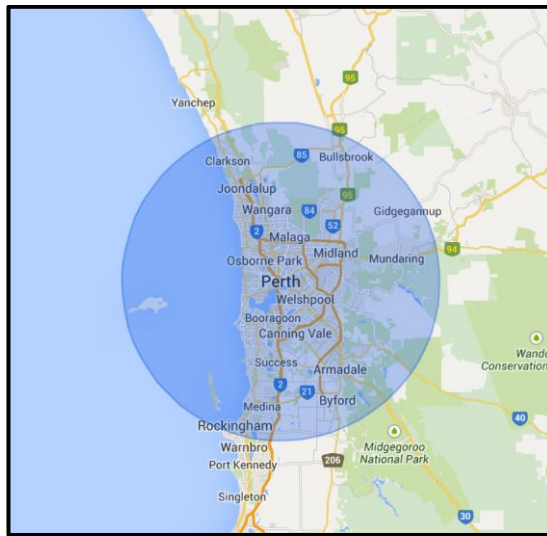
This study focuses on families living in metropolitan Perth, as the experiences of families in rural and regional areas may be affected by distance to appropriate facilities and services. To gain access to participants for this study, disability service providers were contacted in the Perth metropolitan area by email and telephone, and were explained the purpose, significance and methods used in the study. With the assistance of these service providers (through the service providers themselves), information was sent to appropriate clients within their client bases to recruit participants for the study. In addition, I attended a forum conducted by the Future Living Trust and parents were invited to participate by directly contacting to me. Creswell (2014) describes this as “multistage sampling design” where the researcher identifies groups or organisations to gain access to potential participants who will be invited to participate in the study (p. 158).

I had intended to interview between six and ten participants, however I initially only received four responses from the mailout by service providers. Four families indicated interest at the forum and I met with them briefly and provided the consent form, information sheet and contact information to arrange interviews. Unfortunately, none of these four families agreed to progress to interview.

For ethical reasons, I did not approach clients from within my own organisation because of the possibility of the creation of a ‘power imbalance’ or a misconception that participating may affect services delivered to the client (this is especially true in a service provider/client relationship). Ethics approval for recruitment within my own organisation was not granted on this basis. Creswell (2013) states that personal gain for the researcher and the use of ‘rewards’ to participate in the study may create reciprocity between participants and the researcher. It was for this reason that external organisations’ assistance was sought for the recruitment of participants for this study.

Eligibility criteria included being an ageing parent (65 years or over) caring for an adult child with intellectual disability at home, who lives in the Perth metropolitan area, up to 40 kms from Perth CBD (see **Figure 2**). This study does not specify one parent or two parent families, nor consider cultural, values based or religious influences, or socioeconomic status of the families.

**Figure 2:** Map of Perth metropolitan area included in this study



### 3.3 Data Collection

Data was collected from four participant families during semi-structured, face-to-face conversational interviews, where they were invited to share their experiences.

Interviews were conducted over a three-month period. Prior to data collection an external professional transcribing service was engaged for transcription of all of the interviews. However, two of the interviews were complex, (people talking at the same time, external interruptions during the interview), so I transcribed these interviews myself as I considered that I had an advantage being present at those interviews.

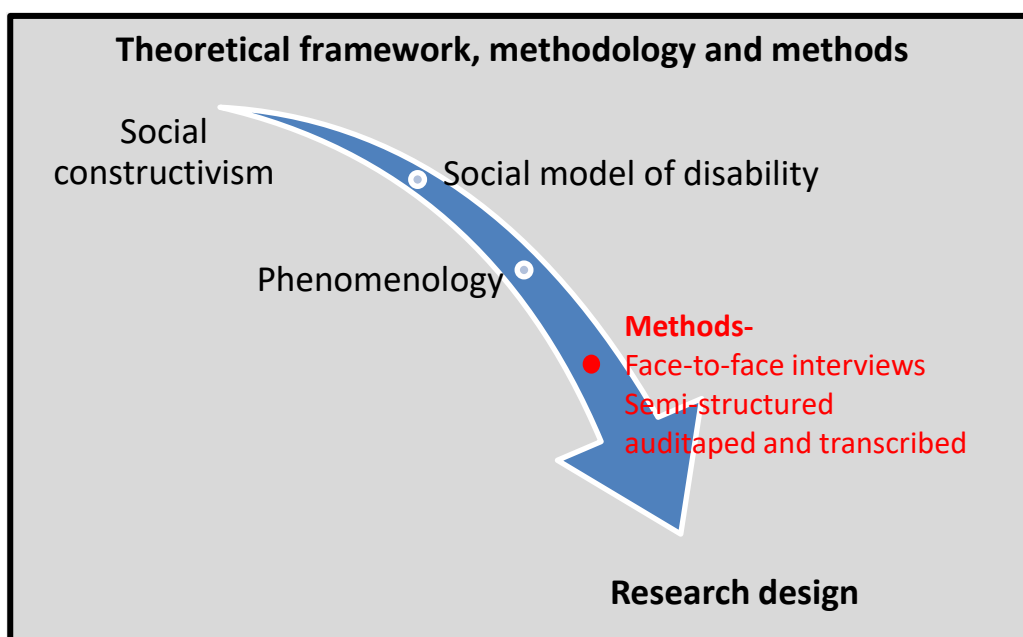
Consideration was given to the likelihood that access to eligible participants may be limited, and the population may be considered ‘hard to reach’ due to the emotive subject matter. Emmel et al. (2013) suggest that understanding the target population, appropriate engagement methods, and understanding “what our sample are willing to discuss with us and why they think it is important” may address some of the barriers that make a population ‘hard to reach’ (pp. 126-127). The development of trust between participants and the researcher may contribute to insight into the experiences of the phenomenon, build rapport and credibility, and address reluctance to participate in research (Emmel et al., 2013). In addition, Emmel et al. (2013) suggest that “participants engage in research because they think it is worthwhile to them” (p. 127).

Within the literature there is some difference of opinion about the sample size for this type of research. Creswell (2014) suggests that the size of the sample depends on the

research design being undertaken, and phenomenology has anywhere from three to 15 participants. Emmel et al. (2013) state that there are no clear guidelines for the sample size, and in a sample of research literature the researchers largely provided no evidence for stating a particular sample size as ideal. It is inevitable that sample sizes are small when conducting phenomenological research because of the detail in the data collected, and to enable manageability of analysis (Emmel et al., 2013). Initially, this study intended to interview between six and ten participant families, however despite interest from eight, the final number recruited and interviewed for this study was four participant families. The size of the sample in phenomenological research may also depend on theoretical data saturation. Data saturation is achieved when gathering further data does not reveal any new or additional insights and therefore continuing with the interviews (or other methods of data collection) will not contribute to the study (Creswell, 2014). However, Emmel et al. (2013) state that theoretical data saturation has weaknesses where the phenomenon to be studied is “explored through detailed and in-depth investigation” (p. 151). Where the experiences of the participants are “relatively homogeneous” because of the limited range of research questions, true data saturation may be difficult to achieve (Emmel et al., 2013, p. 151).

The methods used in this study can now be added to the pictorial representation presented in Figure 1, demonstrating the design of the research with methodology and methods used.

**Figure 3:** Building the design of the research – adding the method component



### ***Data analysis***

This study uses a structured systematic approach to data analysis recommended by Moustakas (1994), which “sets aside” the researcher’s preconceived ideas or opinions (from experience) to enable a greater understanding of the participants experiences, categorises the data, then clusters responses into themes (Creswell, 2013). This approach considers not only *how* phenomenon was experienced by the participants, but also *what* the participants’ experiences were (Creswell, 2013).

Creswell (2013) suggests a ‘simplified version’ of Moustakas’ data analysis method for phenomenological research (p. 193). This simplified version was utilised for this study.

**Table 1** illustrates the process and steps undertaken for the analysis of the data collected.

**Table 1:** Data analysis procedure

<b>Preparing to analyse the data</b>	Clearly identify researcher's personal experiences, opinions and pre-conceived ideas to enable the focus on the participants' experiences. This includes information gathered from the literature review.
<b>Classifying the collected data into themes</b>	List the significant statements and analyse for repetitiveness. Group the statements into "meaning units" or themes.
<b>Interpret the data</b>	Describe what the participants have experienced (the textural description) and how they experienced it (the structural description). This includes a description of the reasons why accommodation isn't sought outside of the family home. It also records information regarding use of respite services and experiences in respite, informal support networks, and plans for the future.
<b>Representing or visualising the data</b>	Develop the 'essence' of the phenomenon. This culminates in a discussion that describes the experiences of the participants and the reasons decisions have been made regarding current and future accommodation support for their adult child with disability.

(Modified from Creswell, 2013, pp. 190-194).

#### ***NVivo software analysis procedure***

NVivo software, a qualitative data analysis package, was used to manage the data collected in the interviews, and to enable a structured organisation of responses and themes. While this study was relatively small, the use of software to enhance the "quality, rigour and trustworthiness of the research" was used in conjunction with

manual analysis, suggested by Welsh (2002) as appropriate to achieve the best results, utilising the best features of each method.

The transcribed interviews were initially uploaded to NVivo, and key search terms were entered to identify common themes (nodes in NVivo). Initially, approximately 18 nodes were identified, which were later clustered into six main nodes, separating the structural descriptions and the textural descriptions. It was important to ensure that the discussion would not focus on elements that were not being researched in this study. For example, the *quality of care* was identified in all of the interviews, relating to the textural descriptions. To keep the focus off ascertaining what ‘quality’ means, as this was not being investigated in this study, terminology used is ‘perceived quality of care’. This reasoning was also applied to experiences in respite as being either ‘perceived negative’ or ‘perceived positive’ experiences.

While analysing the data, some key themes were mentioned several times in the interviews (as they were semi-structured interviews this was expected). To capture these additional responses, the interview transcriptions were re-read and analysed manually, which either synthesised the descriptions or weakened the responses. Welsh (2002) suggests that this process improves the rigour of the analysis by “validating (or not) some of the researcher’s own impressions of the data” (p. 7). In addition, some emerging issues, which were initially thought of as being significant, were not included in the discussion chapter, but ‘set aside’ for further research.

### **3.4 Ethics and risk management**

The research proposal was submitted to the Human Ethics Committee at Edith Cowan University in June 2015. Following approval from the Committee, a draft of the questions for the interviews were provided to families known to me for feedback regarding the suitability, wording and process for recruitment to the study. (Information and feedback during this process was not presented in the thesis.)

Participants for the study were recruited through disability service providers in Perth WA, and through a forum conducted by the Future Living Trust, held in Midland in April 2016. An invitation letter, expression of interest to participate and information sheet (Appendix A, B and C) were sent to service users the disability service providers identified as meeting eligibility criteria, to recruit for the study. This initial information was sent by the service providers because of privacy and data protection considerations.

Following expressions of interest from service users, each potential participant was contacted and a meeting time was arranged. The information sheet was explained in more detail at the meeting, and the potential participant was asked to sign an informed consent form. (Appendix D). No participants withdrew from the research at this stage, or beyond this stage of the research. All data collected, including recordings and transcriptions of interviews, have been kept confidential and rendered non-identifiable. All participants were advised of their right to request a copy of the interview transcriptions and a final copy of the thesis at their request. The participants all declined a copy of the transcriptions but indicated that they would be like to receive a copy of the final thesis. This will be implemented after publication of the thesis.

A risk assessment was carried out prior to any interviews being undertaken, and submitted to the Faculty of Health, Engineering and Science, School of Psychology and Social Science at Edith Cowan University. There is a level of risk to the participants because of the nature of the research and the sensitivity of discussing their own mortality, in addition to experiencing anxiety and stress over their caregiving role. The participant families were made aware of this risk prior to the interviews and were assured that they may withdraw from the study at any time, including during the interview process. In addition, information was made available regarding appropriate counselling services should the participant/s request psychological support.

I also recognised that there was also a level of risk to myself, both physically (due to the location of interviews if conducted in private homes) and psychologically (due to the nature of interviewing and potentially distressing participants). Procedures were put in place to ensure that I was in contact with a responsible adult prior to commencing interviews in private homes, and contact again upon leaving private premises. I had access to an Employee Assistance Program through my workplace in the event that psychological or counselling services were required. Edith Cowan University also has a Counselling Service that is available to all students that can be utilised if required.

### **3.5 Validity and reliability**

The question of validity in qualitative research is raised by several authors, including how qualitative research validity terms and perspectives differ to those utilised in quantitative research. In a comparison of terminology, Noble and Smith (2015) defined validity in quantitative research as “the precision in which the findings accurately reflect



the data”, while reliability is defined as “the consistency of the analytical procedures, including accounting for personal and research method biases that may have influenced the findings” (p. 34). By contrast, in qualitative research alternative terminology for validity and reliability is presented as “truth value”, “consistency”, “trustworthiness” and “conformability”. Noble and Smith (2015) suggest that the methodological strategies used by qualitative researchers to ensure “trustworthiness” replace statistical methods used in quantitative research to establish validity and reliability.

In his evaluation of validation and reliability in qualitative research, Creswell (2013) presents the perspectives and terms utilised by several authors and summarises them to provide an overview for reference. Wolcott (cited in Creswell, 2013) claims “that the term *validation* does not capture the essence of what he seeks” when conducting qualitative research, and the term *understanding* may be more appropriate (p. 247-248). This study seeks meanings of and descriptions of experiences in order to reflect upon and gain a greater understanding of a phenomenon, so it is appropriate to adopt Wolcott’s perspective when considering the validity and reliability of the data collected for this study.

Some of the techniques that were utilised to demonstrate how validity and reliability were considered for this study are suggested by Whittemore, Chase, and Mandle (2001) and include –

- consideration of the design of the research, especially in regards to sampling,
- the generation of data; verbatim transcription,
- demonstrating analytical technique; use of NVivo, conducting an adequate literature review, reflexive practice and bracketing of personal experiences,
- and presentation of findings that acknowledge the perspective of the researcher and provide a ‘thick’ description of the experiences (p. 533).

In addition, the exclusion of participants with retrospective views (their adult child with disability had already left home) may further add to the validity of the research (Cox & Hassard, 2007).

## **Conclusion to the chapter**

The research design utilised in this study considers the theoretical and methodological framework appropriate for a phenomenological study. This chapter has outlined the

methods used in recruitment of participants, data collection and data analysis utilising NVivo software with additional manual analysis. Ethics approval was granted by Edith Cowan University prior to the research being undertaken, and the risks to both the participants and the researcher were identified, along with strategies to reduce any anticipated risk. Finally, discussion of how validity and reliability can be applied to qualitative research, drawing from previous literature, identified the strategies undertaken that demonstrated how the study considered the ‘trustworthiness’ of the data collected.

Chapter 4 presents the results of this study, with verbatim comments from the interviews. The comments are presented in no particular order, and clustered as ‘structural’ and ‘textural’ descriptions of the experiences.

## Chapter 4      Results of the study

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The purpose of this chapter is to present the results of the interviews with the four participant families, and to introduce the key themes that emerged. The results have been ordered to correspond with the research sub questions to ensure that the focus of answering the central research question identified in Chapter 1, was maintained.

For the purpose of this study, the gender of the child with disability is not disclosed as it was not relevant to the results of the research, and may cause identification of some of the participants. If the sample size had been larger, or the person/s with disability had all been the same gender, the genders would have been identified as the risk of identification would have been reduced. It was important to consider the ethical restraints of the study as approved by the Ethics Committee. All answers by the participants that identified a gender, or where the participant referred to their son or daughter with gender specific terminology, have been altered from “he” or “she”, to “they” or “them”, highlighted in italics. While this is not ideal terminology, it was important to maintain confidentiality of the participants and precision in the verbatim responses.

Two of the interviews were with both parents present and active in the interview, one interview had one parent taking the lead role and the other parent not present throughout the whole interview, and one interview was with only one participant as a sole parent. For the analysis, participants are described as “participant family” to further de-identify the data.

The following sections include verbatim responses from the participant families.

### **4.1 Structural descriptions of the phenomenon**

Utilising the data analysis procedure advanced by Moustakas (1994), a structural analysis of the phenomenon as experienced by the participants in the study will first be described. This structural description will “reflect on the setting and context in which the phenomenon was experienced”, and describe the underlying influences on the participants lives, or ‘how’ they experienced the phenomenon (Creswell, 2013, p. 194).

The three components of the structural description are the perception of the ability or independence of the adult with disability, the support and assistance (paid or unpaid)

that the parent/s receive to assist with care, and the parent/s acceptance of the caring role.

### ***Perception of ability or independence***

All of the participant families were asked to describe the support that their son or daughter required at home. In order to understand what supports are required, families were asked to describe their perception of the abilities or independence skills of their son or daughter.

Three of the participants reported that their child was verbal to some extent, though language may have been limited to a few sentences, or due to a speech difficulty (such as a speech impediment) they may be hard to understand and the listener needed to be patient. One family also reported that their child had diminishing skills and abilities due to possible early onset dementia, but didn't disclose if this affected the ability of language, only that their ability to recall name, age and address had diminished. Only one family in the research reported that their child had no language skills. Therefore, instead of the people with disability voicing their understanding of their own abilities or independence themselves, it is important to differentiate between actual ability or independence, to a 'perceived' ability or independence from the parents points of view.

### ***Ability to make choices***

Only one of the participant families expressed that their child verbalised wants and needs well, and made choices, stating more than once during the interview that their child knew what they wanted.

If *they* want to make a point *they* will, and I involve *them* in it. I have never ever said, "you are going to do this". I have often asked *them* if *they* want to live in a group home and *they* say "no. This is my home".

Another family stated that while their child won't initiate a conversation, they are able to say 'yes' or 'no'. However, the participant in this interview thought that it was sometimes unclear if their child really understood the implications of their answer, but may clarify their understanding if their child's actions confirmed it. For example, saying 'yes' to needing the toilet and then walking off to the toilet themselves.

One of the circumstances was quite unique. The participant disclosed that their child had made a decision regarding a life partner and had entered into legal marriage, just

like their other siblings had, however they continued to live at home due to other factors (including appropriate funding). This is discussed further in the textural themes. This participant family also stated that their child had made other decisions in their lifetime regarding work and recreational pursuits.

While one of the participant families reported that their child was non-verbal and had a “severe intellectual disability”, they expressed that they took cues from behaviour as an indication of choices. For example, the family explained that they were aware when their child was tired and need to rest, but expressed this as “they knew when *they* wanted to go to bed”.

*They don't talk, they understand a lot of what's said ... quite a bit of what's going on around them.*

### ***Independence with life skills and personal care***

None of the participant families stated in the interviews that their child had any ability with life skills such as meal preparation, or other household tasks, other than one family reporting that their child was able to make their bed.

*They need help now with medications; you got to cook for them. I mean, they make the bed, but nowhere near like they used to. They are not as tidy as they used to be.*

Due to early onset dementia, this family stated that the ability of their child has deteriorated, and that they now require care for most of a 24 hour period.

For self-care tasks, such as showering, dressing and feeding, only one participant family reported that their child was independent in such tasks.

*They are always very particular in dress. When they go out they dress beautifully. They can look after themselves, shower themselves. It has taken a while to say that they can now shower themselves and is now starting to keep their hair short so it is easier to wash.*

One participant family reported that their child was able to shower independently, however the other two families provide support for all personal care for their child.

Only one participant family commented that they supported their child with arranging medical appointments and managing finances, though it was concluded that this would

be true of the other participant families too, due to the expressed lack of ability of their child to manage other daily tasks.

### ***Support and assistance***

The research also sought information regarding support provided in the home, either formally or informally, for either the parent/s or the adult child with disability to understand the level of supports required to enable the ongoing caring role in the home.

#### ***Practical or emotional unpaid support***

Of the four participant families interviewed, one had a strong network of ‘family’, which included extended family living in Perth and some living in the country. The participant responded that the support the family network provide is moral support, and in the future (following the death or inability of the main carer to provide the current level of care), possibly in a practical sense.

None of the participant families in the research had regular, informal or unpaid support in the home for their son or daughter. Two of the families discussed some occasions in the past where a sibling had assisted in the provision of care due to a hospital visit for the primary carer, or a holiday for the primary carer. One of those families reported that this was a successful arrangement, while the other family stated that it was not very successful.

One family had reported that one of their other children provided some advocacy for their sibling, though no practical support as they had grown older.

The other two participant families reported that they had very little assistance in the past, if any, from family or others, and expressed that they didn’t expect it in the future.

It is worth noting that three of the families interviewed clearly stated that they would not want or expect their other child/children to look after their adult child with disability after they were no longer able to provide the care themselves.

#### ***Paid or formal support***

Only one of the families interviewed had regular publicly-funded paid support in the home to assist with personal care for their son or daughter. One other participant family had private carers, who provide the day community-based support, occasionally assist

or offer to provide morning personal care. Both of the other participant families provide all of the day-to-day personal care for their adult child.

### ***Day activities, work or other support***

The four participant families interviewed all reported that their son or daughter had some form of support or work during the day, to varying degrees. One participant family reported that their child worked five days per week in a supported workplace; another reported that their child was supported in community activities with private carers five days per week, and another supported five days per week by disability service providers. Only one family reported that their child only had limited support one day per week in the community to go to the shops or swimming, and the occasional social club event on a Saturday, subsidised by the family.

### ***Assistance for the carer***

When asked the question “*What supports do you currently receive to assist you personally in the home? This refers to your daily living tasks, assistance with health related conditions, home duties and mobility*” none of the participant families reported that they had any assistance for themselves. One family said that they would look into Home and Community Care support if they needed it, but didn’t believe they were eligible as they received the Australian Government Carer Payment. In addition, none of the participant families received informal or unpaid assistance from relatives or friends for themselves.

### ***Local Area Coordination support***

During the interviews, involvement and contact with Local Area Coordinators (LAC) (provided by the DSC in WA), were discussed. Only one family did not mention any involvement with an LAC, while another expressed mistrust and dissatisfaction with Local Area Coordination services, stating “she said contact me when you need, and I haven’t bothered to do it”.

One family expressed that in the past they had not asked for a lot of support, but did have regular contact with an LAC; “I didn’t know what I was doing, or what I was asking for, or what I needed or what I didn’t need”. More recently this family had the assistance of one of the other children in the family advocating for their sibling, which was reported as a great help.

One participant family reported a good relationship with their LAC and had regular contact, including being involved in future planning for their child and regular new applications for funding for future services.

### ***Reciprocal care***

The literature review revealed that reciprocal caregiving, and interdependent relationships (including a financial one), may influence a parent's reluctance to seek out of home care for their adult child with disability. While this was not a specific question in the interviews, it was apparent that none of the people with disability in this study would be able to offer any form of reciprocal care. It is recognised that if the research sample had been larger, and families who agreed to participate in the research had a son or daughter with a 'higher functioning disability', the responses may have reflected some reciprocal caregiving.

### ***Acceptance of the caring role***

The four interviews revealed similar themes in regards to the families' acceptance of their caring role, and demonstrated a sense of gratification that caring for their son or daughter brought to their lives. This was expressed as "they are lovely", "a delight to have", "it has just been beautiful", "they are good to have around" and "they are good to live with". Far from their son or daughter being a burden, statements included "I feel that is what we are blessed with and that is what I will deal with", "they are our responsibility, and it is up to us what happens to them", "I am very fortunate, I have no worries or complaints" and "it hasn't been a burden, and it is not a burden".

The families also expressed concern regarding the quality of care in accommodation services and that they were the best person/people to provide the care that their son or daughter needed, and would continue providing care to ensure that they received the best possible. One family declared that the care they would receive in accommodation services would never be as good as the care that they could provide themselves, and they would always worry about their child. Another stated;

Nothing but the best will do and I am responsible for them, so I would have to make sure that they are placed where I am perfectly happy with, otherwise I won't - no respite for me.



One family felt that life at home had been very successful, and maintaining this ongoing caring role was the best thing for their family and for their adult child with disability.

Concern for maintaining and providing a quality for life for their adult child was expressed by one family;

They have a right to be treated with dignity, with respect, to allow them to go places, to enjoy life and to die well. They are going to have a good life; they are having a good life.

### ***Siblings within the family***

All four of the participant families have other children as well as their child with disability. Whether or not they receive emotional or practical support from their other children was discussed earlier, however the presence of other children also influenced some of the families' acceptance of the caring role, and impacted on family life.

All four of the families interviewed had unique situations, however in regards to siblings, only one family still had another unmarried adult child living at home. This family's situation was also the only family where the loss of another adult child was revealed (not disability related), and there were no grandchildren.

Another family, with other adult children, commented on the earlier years;

I have brought them up as just as equal as the others, and that is what I feel about it...I did for them all. What I did for one, I did for the lot.

Not all of the comments were as positive however, with one family expressing some discord from their other children;

One of them just recently said, "Do you realise you've got other children as well?" And I know it's been hard for them and I didn't plan it this way... they are looking at it through sibling's eyes not through parent's eyes.

Another comment from one of the families revealed that as their child had grown older, some aggressive behaviours were being experienced, and recognised that caring for their child "was a big job". The family associated this aggression with the disability.

## **4.2 Textural descriptions of the phenomenon**

The textural description of the analysis of phenomenological research, defined by Moustakas (1994), explains 'what' the participants have experienced. These individual

textural experiences by each of the participant families who participated in the research are presented as themes. Three main themes were drawn from the interviews; some demonstrating complexity with several ‘sub-themes’.

The textural themes are the use of respite care in the past and present, the perceived barriers to seeking accommodation out of the family home for their son or daughter, and the planning that the participant families had in place for the future.

### ***Theme one - Respite care – access and past use***

The literature review revealed that there were two opposing opinions regarding how the past use of respite care may influence accommodation choices for families providing in-home care for their adult child with disability. All of the families interviewed had accessed some form of respite in the past or was accessing some form of respite currently.

#### ***Perceived negative experiences***

All four participant families interviewed had past experiences with respite care that they reported as ‘bad experiences’. One family specifically stated that their past bad experience was the triggering factor to continuing to provide care at home;

That is the factor that says, “I’m keeping *them* at home where I can see and know every movement”. I wouldn’t be putting *them* anywhere, never.

All of the participant families with children who were able to verbalise stated that the children themselves demonstrated distress either while in the respite care or after leaving.

We put *them* in the car, as soon as we took off *they* burst into tears, *they* cried the whole way back to home.

*They* came up to me and grabbed me, and you could obviously tell *they* were so distressed, and I vowed and declared that I would never ever put my *child* in such an environment as long as I live.

*They* went just for a weekend, and we would take *them* Friday and pick *them* up on the Sunday. And on the way home *they* said “you needn’t think you are going put me there again”.

All of the participant families considered that the poor level of care or conditions they had experienced in the respite facility was also a factor in their decision to continue to provide care at home (quality of care is discussed further in theme two).

We went to visit *them* one day and it was the last straw, I was not going to leave *them* there, I was not going to walk out and leave *them* there.

It was terrible. I can remember the day I went and picked *them* up, they had all of these people sitting in a room and the TV was so loud it was just impossible to hear yourself or even think...I can still hear the noise, I can still see those children with their hands over their ears. They were sitting there like that, and I thought “what have I done?”

### ***Other negative responses***

Other negative experiences from one or more of the visits to respite accommodation include -

- Two families mentioned that they received no feedback from the care providers’ following a stay in respite accommodation, and felt that this was a negative experience.
- Three families commented that staffing was an issue, and that they had negative experiences with staff specifically.

### ***Perceived as positive experiences***

All of the participant families had at least one experience in respite (which included ‘holiday camp’ accommodation) that was perceived as a positive experience. Most of these positive experiences were since their son or daughter had grown into adulthood.

One family had utilised accommodation provided at Pyrton in the late 1980s and reported that their child was “looked after quite well” there. The family felt that the staff made the difference to the quality of the care their child received.

Staff attributes that instilled confidence for the participant families included staff being “friendly and relaxed”, staff having “a reassuring attitude”, staff demonstrating “genuineness”, and another stated “with a lot of these services ... it’s all about the staff”. One of the participant families reported that a ‘camp’ that their child attended in the past was successful, and attributed the success to the staff member who provided support on a one-to-one basis.

### ***Current respite***

One participant family has current respite support provided in a home situation by a single female carer. The family reported that this was quite successful when they had taken a holiday, and on the last occasion they reported that for the first time had not worried about their child.

You just can't switch off and say, "Oh well, she's got *them* so we're not going to worry about it". Well I sort of can now; otherwise you just don't have a break.

Respite for another family was provided by a supported accommodation provider close to the family home. This had been utilised on a previous occasion which was reported as "it worked", and would be utilised again in the near future. The family expressed a sense of relief that they had some form of respite that was successful.

Two of the participant families do not currently access any form of respite.

### ***Theme two - Perceived barriers to seeking accommodation***

#### ***Perceived quality of care***

Congruent to the literature review, there was an overwhelming sense that the quality, or perceived quality, of care provided in supported accommodation, was a major barrier to seeking other accommodation options. Responses from participant families speak for themselves –

There could be a little bit more care with hygiene, more care with health.

I couldn't bear *them* to be away from us if *they* are going to be hurt or treated like a bit of rubbish.

Some of the care is not what I would regard as being suitable. And yeah, concerns me a lot.

I think there could be a little bit more care taken to food, the preparation, to prepare home cooked meals.

They've got these innocent lives in their hands and these little lives are being abused.

We want *them* with us to know that *they* get the proper care.

I don't seem to be able to trust anybody anymore.

One comment of a previous experience –

It was terrible. It worried me so much. That week I had *them* in there I had a shocking week, I just could not function.

Other examples of perceived poor quality of care include –

- Two of the participant families reported that their son or daughter had received physical injuries while in a respite care arrangement.
- Two participant families commented that they felt their child had been “neglected” while in care.
- One family reported that there had been an unreported medication incident while in a respite service.
- One family had negative experiences with day support services and made formal complaints through the proper channels.

### ***Funding***

A lack of funding to pursue accommodation options was discussed in three of the interviews. One family had resubmitted a funding application on several occasions, and were still unsuccessful:

Twice a year we would resubmit it...like, they are married, they want to be together, you know. But there is always someone whose needs are greater than what ours are.

Another family was concerned about an impending cut to funding for the in-home support they currently receive for their adult child:

They're trying to cut it off, as we're both getting old and now they reckon they haven't got the funding for it to keep it going seven days a week.

For the third family, funding was being sourced to increase the amount of supports in the home to supplement the private carers they currently employ to ‘stretch’; their current funding:

Well, we've been reasonably happy with the funding as it is, but to do what we want to do for our future, we want more hours for our future because we

want to spend more time with our grandchildren and *other children*. So we are looking at some more funding and we have applied for more funding.

### ***Physical environment***

Only one of the participant families reported that a previous respite experience was unacceptable due to the physical environment. A lack of hand rails in the toilet and in the bathroom was hindering safe personal care and independence in personal care, stating “I didn’t think it was very well setup at all for people with disabilities”.

Another participant family had made extensive modifications to their homes over the years with purpose built bathrooms to enable personal care in the home.

### ***Values or religious based considerations***

While there was not a specific question in the interviews asking participants if there were values or religious based reasons for the continuation of in-home care, it was expected that if values or religious reasons were crucial factors in decision making, they would be identified during the course of the interview. Two of the families interviewed mentioned religious beliefs currently and/or in the past, with one of those specifically stating that it had influenced their decision to continue to care at home. The other family also discussed a previous affiliation with a church based facility providing care for other people with disability.

However, in all of the interviews there was an implied suggestion that the participant families held some form of moral duty to provide the care for their son or daughter.

### ***Other barriers***

There were two other barriers mentioned by the participant families –

- The location of accommodation was important to one family, it would have to be close to the family home “so we could drop around and see how *they’re* going”
- One family stated that they didn’t know where to look for permanent supported accommodation

### ***Theme three - Plans for the future***

All of the participant families had some form of planning in place for the future care for their son or daughter. This ranged from requests written into a will (financial

arrangements or care arrangements), specific plans for future housing, and support from other family members.

In the course of the interviews, the Future Living Trust was discussed by two of the participant families as having played a role in planning or the writing of wills. The Future Living Trust was introduced in Chapter 2, and will be discussed further in Chapter 5.

### ***Financial plans***

Three of the participant families had wills in place that made allowances for financial support in the future for their son or daughter, sharing the proceeds of the estate among their adult children evenly. The other participant family had not bequeathed money to their adult child, but had left specific instructions in their Will to allow for lifelong accommodation in the family home, before the estate could be sold. This family noted that with Government funding their adult child would be able to share the home with another person with disability.

Of specific note is the following -

- three of the families had only recently written wills,
- one family had “coordinated” the writing of wills with their other adult child to ensure that their son or daughter with disability was provided for financially,
- one family specifically mentioned that upon the death of the remaining family members and their child with disability, any funds left over from the estate were to be distributed to the Future Living Trust “to help others to be able to have, and live independently, and to be looked after”.

### ***Guardianship and care requests in wills***

None of the families indicated that they currently had guardianship over their son or daughter, and none had any plans in place for future guardianship when they were no longer able to provide practical support. Specific information included –

- one family commented that while they had written information and requests of how their son or daughter would be cared for after their death into their wills, it was acknowledged that this information “was a bit vague”,
- two families mentioned that they had some form of contact or assistance from the Future Living Trust in Perth,

- only two of the families had made specific plans in regards to future care and had this written into wills.

### ***Accommodation plans***

One of the participant families had undergone home modifications in the past to allow for the in-home care for their child, and further plans for home modifications were in place for the future to allow for separate accommodation for their adult child and carer. This was also a direction in this family's will, that their child would remain in the family home until "*they* no longer needed it". The estate could only then be distributed to the beneficiaries of the will.

Another participant family had appointed two executors from within their extended family who would also play a role in overseeing medical and financial needs for their adult child. The family has planned for their adult child to continue to be cared for in the family home with the assistance of carers.

The other two families interviewed had no plans for accommodation for their adult child when they were no longer able to provide the care themselves, though one of these families had explored permanent accommodation options in the past without success (this resulted in one of the negative experiences discussed earlier). The other family felt that with the appropriate funding they would be able to place their adult child in a suitable permanent accommodation out of home.

## **Conclusion to the chapter**

The results of the interviews were ordered to align with the sub-questions identified in Chapter 1 and clustered under 'structural descriptions' and 'textural descriptions'. It was intended that this process would guide the discussion and allow the emerging themes to either 'find a place' in the study, or be put aside for further consideration in future research. This process also enabled clear focus on answering the research question, and ensured that reoccurring comments from the participant families were captured. The results were presented without identifying the gender of the person with disability, as it was not apparent that the gender of their child had influenced decisions that the parents had made.

Chapter 5 is a discussion of the results and provides an in-depth analysis and interpretation of the key themes that emerged during the interviews. The discussion



answers the research questions presented in Chapter 1, and explains how the results support the answers. The Chapter concludes with the presentation of some issues that emerged as a result of the interviews.

## Chapter 5 Discussion

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The central question for this study asked “*what factors influence the decisions made by ageing parent carers of adults with intellectual disability to continue to provide care and support in the family home?*” Semi-structured interview questions sought to explore variables and barriers that might have determined why decisions were made and what plans and hopes parents have for the future accommodation and care of their adult child with intellectual disability when they are no longer able to provide the care themselves.

The discussion begins with the ability and independence of the adult with disability, the lack of informal support and varying levels of formal support and services the families currently access, and how the families’ opinions of perceived quality of care in accommodation services had affected their decision to continue to provide care in the family home. Discussion also includes planning the families had in place in their wills, either financial or for specific care requests (or both), and the lack of guardianship appointment present in this study. While the impact that the full implementation of the NDIS is not yet known, discussion will include how the NDIS could potentially influence the planning process for families in the future.

The responses from the participants relating to their perception of the ability and independence of their son or daughter were reported as ranging from minimal support for self-care to full support for all activities of daily living. The purpose of this question was to ascertain if there is a link between the level of support that is required for their son or daughter and if this influences the ongoing provision of support in the family home.

This study revealed that the level of disability, or the perceived ability or independence, of their son or daughter appeared to have little or no impact on the decision to provide care in the family home for the participants in this study at this stage in their lives. The responses indicated a range of abilities of their adult child, from being able to communicate (though limited), to no verbal language at all; mobile with no difficulty walking, to full use of a wheelchair; able to shower, dress and eat independently, to being fully reliant on carers for all self-care.

The adult children in the families in this study would all be categorised as having a ‘more severe’ disability utilising the definitions provided by the ABS for the Survey of Disability, Ageing and Carers (SDAC) introduced earlier. The SDAC defined ‘profound or severe disability’ as a person who was either “unable to do a core activity task...sometimes needed help or supervision with a core activity task, or had difficulty understanding or being understood”; while those with a ‘moderate to mild disability’ may not need assistance or only have some difficulty with one or more with core activity tasks, or need aids or equipment to carry out tasks (Australian Bureau of Statistics, 2012a; Qu et al., 2012, p. 3). According to the SDAC, a parent carer is more likely to continue to provide care in the home if their son or daughter was considered to have a ‘milder disability’, and likewise if the disability is considered ‘more severe’ they would be less likely to continue to provide care in the home as they age (McConkey et al., 2011; Qu et al., 2012). As all parent carers in this study were over the age of 65, it could be assumed that the majority of their adult children would be categorised in the ‘milder disability’ category according to the SDAC criteria. However, this was not the case, therefore the results from this study are contrary to the findings in the SDAC (2009).

It is important to recognise that the SDAC is a survey where people ‘self-report’ disability and caring status (Australian Bureau of Statistics, 2012a), and therefore it is important to recognise the limitations of the classification of severity of disability in the SDAC. Furthermore, the categorisation parameters utilised for SDAC may be considered subjective. Potentially, as a family carer has lived with their child with intellectual disability all of their lives, they could understate the ‘severity’ of their disability, or the support that their child needs for activities of daily living. In addition, parent carers may have difficulty identifying themselves as carers at all, and consider that the support they provide is a part of their role as a parent.

The explanatory notes for the SDAC state that:

The need for help may have been underestimated as some people may not have admitted needing help because of such things as a desire to remain independent, or may not have realised help was needed with a task because help had always been received with that task (Australian Bureau of Statistics, 2012a).

While categorising the adult children in this study as those with a ‘more severe’ disability may be subjective and based on anecdotal evidence, the parents interviewed all considered themselves carers, and reported providing full support for one or more core activity for their son or daughter. In this sense, the families in this study could be classified as ‘atypical’ when comparing them to the statistics as a result of the SDAC. An explanation for this could be that even though the parent carers in this study were over the age of 65 years (if a couple were interviewed, at least one of the couple were over the age of 65 years), none of the parents reported a physical limitation that may be expected in an older age bracket.

Following the enquiry into the perceived ability and independence of their son or daughter, participants were asked if they had an informal network of unpaid support to assist with the provision of support in the home, and if their son or daughter currently accessed formal (paid) services. These questions were included to ascertain if the level of support received makes a difference to the likelihood that ongoing care will be provided in the family home.

Despite the parents in this study not receiving any informal support from their other children or family members to assist with the care of their son or daughter with disability, they continued in their caring role as they aged. A previous study (Bowey & McGlaughlin, 2007) found that where informal supports were provided in the home, carers were more likely to continue in the caring role, and less likely to have made future plans for their son or daughter. Assumptions have been made that the carer burden was reduced when there was an informal support network, or that care would be provided by people within that informal network when parent carers are no longer able to provide the care themselves (Bowey & McGlaughlin, 2007). A possible explanation for this disparity could be attributed to the size and demographics of the sample used in this study, including the potential for these results to differ if the parent carers were older or more infirm.

In addition, none of the participant families expected any of their other children to provide care when they were no longer able to do so, with three of the families stating that their other children had families and ‘lives of their own’ which make it difficult, in a practical sense, for them to assist their parents. There was also no evidence that emerged from this study that suggested that a large family would increase the likelihood that informal support would be provided, with between one and three other adult

children in the families interviewed for this study. The participant family with only one other adult child (also co-resident in the family home) reported that while they had a strong family network from the extended family providing ‘moral support’, there was no regular informal practical support provided by any family members.

The participant families in this study were all known to service providers and accessed a range of funded formal supports for their son or daughter with disability. As participants were recruited through service providers, this was expected, however this study revealed a level of disengagement, and evidence of ‘selective’ use of formal services. It was difficult to ascertain if the amount of formal support influenced the decisions to continue to care at home for the families in this study, however it did appear that the more complex the disability reported by the family, the greater amount of support that was received. This is also true of the level of engagement between the participants in this study and a Local Area Coordinator.

While the participant families in this study could not be considered as ‘slipping through the gaps’, as they make choices regarding the services they currently access, the results suggest that service providers may make assumptions regarding the size of the family, existence of informal supports, and lack of engagement with formal support to indicate that no support or assistance is required. This was clear in two of the interviews in this study when reporting on the contact with their LAC, with comments such as “she said contact me when you need, and I haven’t bothered to do it” and “I didn’t know what I was doing, or what I was asking for, or what I needed or what I didn’t need”. As circumstances change, parents get older, and the complexities of the level of disability their son or daughter experience changes, families may require access to services they had not utilised previously, or require services and advice that they are not aware exists.

This study also found that none of the participant families received any formal support for themselves, despite being eligible. The purpose of including this in the questioning in this study was to ascertain if any of the families received formal aged care supports to assist in their caring role. This was also to determine if the sample in this study reflected the findings by Qu et al. (2012), who stated that 67% of mother carers over 65 years of age had some form of disability themselves, and therefore may need help to continue to care at home for their son or daughter. While the response from one family was that “if they needed support they may look into it”, it was not apparent in this study that any of the participant families required assistance for themselves in their home. Even though

three of the parents reported recent or future medical or surgical interventions, the impression given during the interviews indicated that all were intensely proud of their independence and coping skills, which could be an explanation of their reluctance to ask for help.

There was no evidence in this study that indicated there was a reciprocal caregiving role between an ageing parent carer and an adult child with intellectual disability, despite this being a recurring theme in the literature (Cuskelly, 2006; Heller & Caldwell, 2006; Prosser, 1997; Ward, 2011). The existence of a reciprocal care relationship could be considered a form of support to ageing parent carers to enable an adult child with disability to remain in the family home, and to enable a parent carer to continue in their caring role. Possible explanations for the non-emergence of a reciprocal caregiving role for the participants in this study could include technical aspects, such as sample size or the characteristics of the sample selected; or sociological aspects, such as cultural influences or environmental factors.

One of the methodological aspects of the study is the demographics of the sample selected, with parent age possibly the greatest influence. Selection of participants from an older age group could alter the responses in regards to assistance required in the home significantly due to age related health or medical issues. In addition, as the parents interviewed appeared to have good physical health, this would negate the necessity for a reciprocal care arrangement. The relevance of two parent families who provide support at home also requires further investigation, as three of the participant families interviewed were a couple. In addition, it appeared unlikely that a reciprocal caregiving relationship would be present in the families in this study due to the characteristics of the adult with the disability. As discussed earlier, the 'category of disability' of the adult children in the families interviewed as defined by the SDAC would fall into the 'more severe' disability category, which would limit the assistance they could provide to their parent/s.

The sociological aspects that could influence the non-emergence of reciprocal caregiving include the cultural and values based beliefs of the families interviewed. This variable was not explored in detail in this study. In addition to this, the built environment, aids, equipment and modifications to the home, all influence the capacity to continue to provide care in the family home. It is difficult to draw conclusions regarding the influence these variables have on decisions the families have made,

though it is likely that these factors could be a further explanation for the non-emergence of reciprocal caregiving in this study.

Another key issue that arose from this study is the lack of financial support that acts as a barrier to finding suitable supported accommodation out of the family home. One family in the study has had several unsuccessful attempts through the Combined Application Process (CAP) at securing accommodation funding that would allow their adult child to move to supported accommodation with *their* spouse. They commented that “there is always someone whose needs are greater”. It is disappointing that this has not been considered a ‘crisis’ situation that the CAP funding is designed to address (Community Development and Justice Standing Committee, 2014). From a human rights perspective, referring to the ideology of “social role valorisation”, this unsuccessful application is far from the mark of achieving equality. The family’s comments also gave some insight as why they stepped forward to participate in this study:

We can only hope that...and this is why I have been keen to do this today, because I feel ok, it is probably too late for us, then there is others that are coming up the track that need this sort of thing and it is not fair that they can’t get it.

Once parents had decided not to pursue funding due to several unsuccessful applications, they may be ‘lost’ to the system, which will impact on the true number of people with unmet needs. In addition, the number of families who are not registered with DSC is unknown. Therefore, the measure of unmet need is even less reliable. The Productivity Commission Inquiry Report (2011) into a national disability support scheme (the background of the NDIS) also highlighted the extent of unmet need within the sector and the unreliability of data collected because informal support often ‘filled the gap’.

This study found that perceived quality of care in accommodation services was a major barrier that families felt had contributed to their reluctance to seek out of home accommodation, and confirmed the connection between the past negative experiences in respite and the perceived quality of care in accommodation services found in previous studies. All of the participant families in this study expressed a satisfaction with their current caring role and dissatisfaction with the quality of the provision of care by others.

All participant families had past experiences in respite care, ranging from a weekend to up to a few years, which were reported as ‘negative’. It is understandable that a negative experience may have left an indelible mark in a parent’s memory that could influence accommodation choices in the future for their child. “These carers often have long memories of negative experiences of institutional care which may be difficult to forget” (Bowey & McGlaughlin, 2007, p. 50). Two of the participant families had only accessed respite care when their son or daughter was very young, yet the negative experiences had remained with them since then. One family had only one experience in a respite facility and had never utilised respite again, stating “I vowed and declared that I would never ever put my child in such an environment as long as I live”.

The responses from this participant family highlight the importance of experiences in respite care and the impact that these experiences have on family carers’ perception of quality in accommodation services. Bowey and McGlaughlin (2007) clarify this further;

Their views about future housing often stemmed from experiences with short-break provision, which was not always received positively. This emphasizes that the quality of short-break services plays an important role in planning for the future, as it may represent families’ only knowledge of housing provision (p. 49).

Participant families in this study also felt that the staff made a difference to the quality of care their son or daughter had received in the past. The large number of staff required to provide 24 hour care 7 days a week for a person living in a group home raises a question of consistency of care, particularly if the focus of service provision is organisational and staff-centred, as opposed to person-centred practices (Bigby et al., 2014). Furthermore, Bigby et al. (2014) suggested that the quality of care in group homes may be overestimated by organisations and staff, and systematic observation of staff practices are required to make an informed judgement of the quality of service delivery.

This study included questioning regarding planning for the future, and enquired “*what plans, if any, are in place for the person with disability when the parent is unable to continue to provide support in the home due to illness or death?*” This question was designed to ascertain the level of planning undertaken by the families, and the factors



that they felt had either encouraged or discouraged planning for the future, as well as raise the difficult issue of discussing mortality.

It was not obvious in this study that the families had any difficulty discussing their own mortality, despite this being present in other studies (Bigby, 1996; Grey et al., 2015; Heller & Caldwell, 2006). The issue of one's own mortality is an emotive one and a subject that may be considered painful to broach. The emotional and confrontational nature of considering your own death or that of your partner may be in itself a barrier to making future plans. Potentially, more direct questioning regarding mortality may have drawn some inherent responses from the participants in this study regarding the difficulty in planning when they were considering a time when they could no longer provide care for their son or daughter. Furthermore, the participants in this study volunteered to be involved, therefore demonstrating that they were prepared to discuss their own mortality.

All of the families had some planning in place for the future in the form of a will, consistent with the study by Davys and Haigh (2008). All but one of the families had divided their estate evenly amongst their children, with one family preferring instead to make specific directions to enable a "home for life", taking into account that they felt their child with disability would have government funding in place that would be sufficient to provide financial support. However, the allocation of an estate divided evenly amongst beneficiaries may not be considered a specific plan to provide support for their child with intellectual disability, but a 'typical' structure of a will where there is more than one sibling beneficiary.

The results of this study highlight the need for dialogue with parents in regards to 'futures planning' that clearly reflect the preferences for accommodation for their son or daughter when they are no longer providing care, to ensure that the 'voices' of the parents are heard. The study also raised concerns that wishes may not be carried out as outlined in a will. Only one of the families had written a will with explicit key person plans with the assistance of the Future Living Trust (discussed in Chapter 2), and stated that requests were in the will that incorporated accommodation plans as well as allocating executors of the will from within the family. While having stated specific plans for their adult child with disability, the family doubted the stability of their wishes in their will. There is a risk that a beneficiary may contest the financial aspect of the will, or fail to carry out the wishes of their parents written in their wills.

None of the families in this study had legal guardianship over their son or daughter, or had appointed anyone else as a legal guardian for their son or daughter. In the absence of the parents, legal arrangements would need to be robust to ensure that the vulnerability of the person with the disability is protected, and “who might be trusted to always act in the child’s best interest as well as help realise their aspirations for future independent living” (Franz et al., 2014, pp. 66-67). One of the families had requested a “home for life” for their adult child with disability in their will, but recognised that if care was required in an emergency situation “the LAC and emergency plans will probably have *them* put into a group home”. Franz et al. (2014) highlighted the difficulty in the legal aspect of providing a “home for life” following the death of the owners of a property (p. 67). The appointment of a legal guardian could ensure that the wishes of the parents are fulfilled when the parents are no longer able to provide care. This also reinforces the reasoning for an explicit key person (or persons) advocated by Bigby (1996), as it allows for flexibility in the planning process, avoiding ‘locking’ a person with disability into potentially unsuitable accommodation in the future.

The NDIS implementation may see more families seeking flexible funding to allow more choice and control, and enable families to maintain an informal supported living arrangement. What this means to the families in this study is that their wishes and aspirations for their adult child to be cared for in the family home in the future may be funded appropriately and long term by the NDIS. The Productivity Commission Report (2011) proposing the establishment of the NDIS, recognised the role of the ‘informal carer’ and addressed the uncertainty and anxiety that informal carers experience, and therefore recommended life-long planning as a service available to families. While the NDIS is still in the trial stages in WA, the NDIS National Price Guide ACT/SA/WA/NT (released in May 2016) does not extend to allowing provision for funds to assist families with the future planning process. The National Disability Insurance Agency state that funding will be provided for “supports aimed at increasing the sustainability of family caring arrangement”, but this only extends to providing additional support in the family home, not the planning process required for the future (The National Disability Insurance Scheme, n.d.).

## **Emerging issues**

The lack of housing stock, sibling resentment and the suitability of the physical environment in permanent accommodation were all raised as emerging issues in the interviews, however they were not explored in detail within the parameters of this study. These issues will now be discussed in brief.

None of the participant families mentioned that a lack of actual housing stock was the reason they had not sought out of home care, despite this emerging as one of the sub-themes in the literature review. An explanation for this could be that the families interviewed for this study had not progressed to actually seeking permanent housing out of the family home, therefore were not aware of the availability of housing in itself. Only one family had applied for funding, but that was to support their adult child to cohabitate with *their* spouse in existing accommodation. In addition, it was not apparent that any of the families had knowledge or experience of alternatives to supported accommodation other than group home accommodation.

One of the families suggested that their other children had some resentment that their sibling with disability was a focus of their parents' lives, especially as they aged. This was not explored further for this study as it was not identified as a factor that influenced decision making in the literature review.

The perceived suitability of the physical environment emerged as a potential barrier to seeking respite for one family in this study. It was not within the scope of this study to assess or evaluate disability accommodation for modifications that would cater for people with disability. With varying abilities and physical issues that people with disability experience, not all disability accommodation would be expected to meet all needs, which in a practical sense could add to the availability of (or lack of) suitable accommodation.

## **Conclusion to the chapter**

This study has found that the level of informal and formal support appeared to have little or no impact on the decision to continue to provide care at home for the participants in this study. Utilising the SDAC parameters as a guide, the adult child with disability in these families have been 'categorised' as having a 'more severe' disability, yet remain in the family home being cared for by ageing parents. This is in

contrast to the results of the SDAC (2009). In addition, in this study there was no evidence of a reciprocal caregiving relationship between the parent and adult child with disability.

Access to adequate funding was revealed as a barrier to finding accommodation out of the family home. However, there is a likelihood that the number of families seeking funding for accommodation may be skewed as families no longer continue to apply after failed funding application attempts, therefore misrepresenting the extend of unmet need.

The perceived quality of care in supported accommodation was reported as the greatest barrier that has influenced the families' decisions regarding out of home accommodation support, mostly influenced by previous experiences in respite care. In addition, although all of the families had wills in place that provided some guidance or financial plans for the future support for their son or daughter with intellectual disability, the study has shown that the families had some doubts regarding the stability of these plans, which is congruent to the literature.

The final chapter will now summarise the thesis and present recommendations based on the results of this study, supported by the main factors that emerged as an influence for the ageing parent carers to continue to provide care in the family home for their son or daughter with intellectual disability.

## Chapter 6      Summary and recommendations

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As discussed in the Chapter 1, personal experience working in disability services led to a desire to understand what was happening in the disability sector for ageing parents who continue to provide care for an adult child with intellectual disability. The aim of the study was to understand the lived experiences of ageing parents of adults with intellectual disability whom they continue to support in the family home, and to gain an understanding of the decisions regarding future living arrangements, what barriers are in play that hinder future planning, and what plans have been made (if any) for the time that the parent is no longer able to provide care. It was always the intention of this study to improve the outcomes for families and people with disability. As the study progressed it became apparent that the barriers that were assumed to have the greatest influence on the decision to continue to provide care prior to commencing the research were not going to emerge as the most notable. The diverse experiences of the families in the study demonstrated the complexities of caring for an adult child with disability, yet the apprehension felt when considering the future when they can no longer provide the care was not dissimilar.

The journey of this study progressed through the trajectory of the historical context of disability accommodation services in WA, through to the introduction of the NDIS and considering how it might influence the future lives of people with disability in Australia. The emotive nature of interviewing parents and asking them to consider a time when they are no longer able to support their child in the way they have been throughout most of their lives, was expected to cause some distress to either the interviewee or the interviewer, however this was not the case. The interviews were inspiring, and participants demonstrated an embodiment of satisfaction with their caring role, and an expression that they ‘wouldn’t have it any other way’.

The participant families overwhelmingly shared the opinion that they perceived the quality of care in accommodation services as ‘not good enough’ for their son or daughter. Is this any different from what all parents expect? Since the formation of the parent led groups in WA in the early 1950s, the voices of the parents have been heard to enable advocacy on behalf of their sons and daughters for the right to live full and active lives, and to take a valued role in society. Changes to policy and practices will continue to see improvements in disability services as long as research is ongoing, to ensure that

the current and future needs of those who have little or no voice themselves is heard through their greatest advocates, their parents.

The findings of this study suggest recommendations with implications for policy, practice and future research. Key recommendations include policy changes to increase quality monitoring and accreditation in disability respite and accommodation homes to improve first and subsequent experiences in out of home care, and the inclusion of funding in the NDIS pricing structure for life-long planning. A further recommendation is also made to introduce education for service providers, LACs and NDIS Planners, to ensure they are aware of the challenges that parents face as they age and continue to care at home, and to better equip them to provide the information and support for planning for the future for families. This initiative could be supported by organisations such as the Future Living Trust, which has emerged as a resource for families to facilitate the planning process and assist with navigating the legal system, yet does not appear to be widely known. The chapter concludes with recommendations for future research and identifies the limitations of the study.

## **Recommendation 1**

### ***Service monitoring and formal accreditation***

As a result of the findings, it is recommended that all respite and permanent accommodation homes for people with disability undergo a process of regular observation and monitoring, potentially leading to a formal accreditation process. Strategies to improve service users' confidence in the quality of care in disability respite and accommodation homes must involve improving the first and subsequent experiences in out of home care.

Regular observation and monitoring through the introduction of a community visitor program could ensure that disability accommodation services provide appropriate and quality support to residents and encompass person-centred approaches to care. In Victoria, a community visitor program was established operated by the Office of the Public Advocate following the implementation of the *Disability Act 2006*. Appointed volunteers visit residential disability services, including respite homes, unannounced and at random at least once every month to ensure that residents are being supported in their home with dignity and respect, in addition to investigating any concerns and

complaints (Victorian Government, 2011). Reports are provided following every visit to the Department of Health and Human Services or the Office of the Public Advocate.

The expansion of the Council of Official Visitors (a service currently providing advocacy and monitoring of mental health facilities in Western Australia) to include disability housing, could provide an independent monitoring service similar to the community visitor program in Victoria. Currently Official Visitors provide individual advocacy for patients and investigate complaints in mental health facilities, hospital wards and psychiatric hostels, and conduct monthly and bimonthly inspections (Council of Official Visitors, 2015). These visits are unannounced and at a range of times of the day. The importance of regular, unannounced visits to group homes was highlighted by Bigby et al. (2014) who suggest that they would “capture both the nature and consistency of staff practices”, and would act as an adjunct to the “inspection of paperwork or interview with staff in judging the quality of a group home” (p. 364).

To complement a community visitors program, and to enhance the existing quality evaluation process for disability services, a formal accreditation process for every disability residential and respite service would reinforce continuous improvement and instil confidence in service quality for current and future service users. Currently, quality evaluations require disability service providers to complete a self-assessment every year, and undergo an independent quality assessment every three years, where organisations are assessed against the Disability Service Standards (Disability Services Commission, 2014). However, the ability for an organisation to meet the minimum standards is not a measure of quality. A service may meet those minimum standards, yet not provide a service that families perceive as ‘a quality service’. The Australian Aged Care Quality Agency accreditation process, outlined in legislation in the *Quality Agency Act 2013* and the *Aged Care Act 1997* (Australian Aged Care Quality Agency, n.d.), includes unannounced quality assessment visits (a minimum of one per year) and scheduled three yearly assessments for accreditation by a team of quality assessors. In addition, in order to receive government subsidies, aged care homes must achieve this accreditation. Successful accreditation for disability housing could be linked to government or NDIS subsidies in a similar way.

Until the experiences of care provided in short and long term accommodation for people with disability are improved, families like those interviewed for this study may continue to express their concern at the level of care (perceived or real), which will continue to

act as a barrier for planning for the future. The families in this study are in an age bracket that has seen major reform in disability services and accommodation since deinstitutionalisation, and previous experiences in respite may have been decades earlier. Therefore, future planning and policy development must take this cohort into consideration and develop robust quality assessment processes to allow informed decisions when considering future housing for their adult child with intellectual disability.

## **Recommendation 2**

### ***Funding to allow for life-long planning***

As the NDIS is implemented fully across Australia over the next few years, funds need to be allocated to assist with life-long planning processes. Funding for life-long planning is not listed in the NDIS funding and price guide, which governs the associated pricing for funded supports for participants in the scheme since the trial sites for the NDIS commenced in 2014, yet it was recommended by the Productivity Commission in 2011 in the proposal for the NDIS. As the Western Australian 'version' of the NDIS is announced late in 2016, it is an appropriate time for funding for life-long planning to be added to the NDIS Price Guide. This highlights the need for disability service organisations to be aware of the recommendations made by the Productivity Commission, so that the organisations themselves can advocate at a state and national level for the inclusion of funding for life-long planning into the NDIS Price Guide.

As WA adjusts to the new scheme from July 2017, the time to navigate a new pricing structure, governance to overcome operational demands and funding changes, will in itself be a challenge for disability service organisations. Potentially, this could mean that assistance for families providing care at home for an adult child with intellectual disability will slip further off the agenda, and this real and growing demand for permanent accommodation as parents age and can no longer provide care at home will continue to cause uncertainty and anxiety for these families, recognised by the Productivity Commission as far back as 2011.



### **Recommendation 3**

#### ***Education for service providers***

The results of this study challenge the assumption that the lack of engagement with formal support networks indicate that there is no requirement for additional support. Furthermore, this study found that size of the family is not an indication that informal support is in place to assist in the caring role for ageing parents. Education for service providers, LACs and NDIS Planners is required to provide knowledge of challenges parent carers face as they age yet continue to care at home, to ensure that families do not 'slip through the gaps' because of a lack of engagement, or low levels of engagement, with formal services. Strategies to ensure that once families are 'active in the system' service providers, LACs and NDIS Planners don't make assumptions that additional services or increased services are not required until the parents ask for help, as a significant message that arose from this study was the satisfaction with the caring role, a 'moral duty' the parents felt towards their caring role, and a reluctance to ask for help.

The introduction of appropriate in-service training to upskill the workforce will enable identification of families who may need assistance to navigate the legal system. Even though the families in this study were all accessing some formal services, it was evident that there were 'knowledge gaps' in regards to specific services. Previous research found that a lack of knowledge of support services was a barrier to planning for the future. Appropriate education, information and assistance to navigate services are strategies that could be implemented to inform older parent carers about their options (Bigby, 2004).

#### ***Funding to support or extend Trust planning***

This study revealed that help is 'out there' to assist families with the legal processes, trust accounts and wills. The Future Living Trust currently operates in Perth, though knowledge of this service did not appear to be wide spread. Ensuring that the disability workforce have this knowledge is likely to add to the demand for trust planning and paralegal services. The potential for other organisations to provide a futures planning service to families with a child with disability similar to the model that the Future Living Trust utilises, has definite scope. As a not-for-profit organisation, the Future Living Trust is reliant on donations, bequests and fundraising, but with the assistance from State or Federal Government, funding could either extend the operations of the

Future Living Trust, or provide opportunities to other organisations to offer services to every family for futures planning.

The fact that despite my background in disability services in Perth, it was only when researching for this study that I learnt about the Future Living Trust, which had been in operation since the 1980s, is another indication that knowledge of this service is not wide spread.

## **Recommendations for future research**

There were a number of topics that arose that would benefit from further research. In particular, some themes that were evident in the literature review did not present in the data in this study.

The non-emergence of reciprocal caregiving in the families interviewed highlighted the need for further research into the variables that may have influenced this. The variables identified include parent age and physical health, cultural influences on the 'moral duty' to provide lifelong care, and two parent families who continue to care to at home for their adult child with intellectual disability. Three of the families interviewed in this study were two parent families. However, without further research and an increased sample size, no conclusions can be drawn of the significance of this.

The availability of actual housing stock was not explored in this study. The families in this study had not actually progressed to the stage of seeking supported accommodation, or had chosen group home living as an option for their adult child, therefore were not aware of the availability of housing stock in WA. Further research could explore the available housing options in WA, and include time on waitlists for funding and housing, the consideration of individual supported living arrangements, and measure the impact that the implementation of the NDIS has had on housing tenure for people with disability.

An additional theme that emerged in this study is the role of siblings in the family dynamics, and the influence, if any, that siblings had on the decision that parents made to continue to provide care at home. Feelings of resentment that parents were focusing on their child with disability did emerge in one of the families in this study, however this was not the focus of this study and could benefit from further research.

Furthermore, research on the effect of ageing of the person with disability would add a further perspective for families who continue to provide care at home.

## **Limitations**

As the size of the sample in this study was small, and there was only one male with disability in the study, it had limitations that included ‘gender specific’ responses regarding the person/s with disability. Ethical considerations of confidentiality needed to be a priority so that the participants were not identifiable in the thesis, therefore the decision was made to de-identify the responses with non-gender specific terminology. To address gender identification, it could have been possible to limit the study to a single gender, however, this would also have further reduced the sample size.

It was beyond the scope of this study to gain feedback and responses from people with intellectual disability on *their* preferences for future accommodation options, because the nature of intellectual disability could have required alternative and augmentative methods of communication, and specialist staff to conduct the interviews. In addition to this, the focus of the research was about the carers’ perceptions about their experiences and choices. The study also did not delve into the carer’s knowledge of alternative supported living options other than group homes, or consider how their perceptions of alternative accommodation may be altered if appropriate information was provided to them regarding this.

The research was also limited to families who were already accessing disability services through a service provider. This is because access to participants for this study was through disability service providers. It would be implausible to claim that this is a representative of the population as this study utilised a phenomenological approach to research, and the sample size could influence the results. This study was also limited by location; the majority of disability service providers in WA are within 40 kilometres of the Perth CBD. However, this limitation was purposefully selected to ensure that the data was not unduly influenced by distance to available services.

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## **Appendix A - Letter to potential participants**

Dear .....

### **Re: Invitation to participate in research**

My name is Wendy Simpson, and I am a research student at Edith Cowan University, undertaking a Masters by Research Degree. I am researching the decisions parents make when deciding the accommodation options for their adult child with an intellectual disability.

I am currently recruiting for the research project, where I will interview parents/parent at a location of their choice (the family home is suitable for this). The criteria for being a part of this study include –

- being aged over 65 years and continue to have an adult child with an intellectual disability living at home with them, (you may be a single parent or a couple)
- living in the Perth metropolitan area (within a 40 km radius of the Perth CBD)
- willing to undertake an interview lasting approximately 1 ½ - 2 hours.

I have included an information sheet outlining the proposed research in greater detail. I am happy to answer any specific questions you may have to enable you to make the decision to participate. I may be contacted on 0403355114, or by email at [wsimpso0@our.ecu.edu.au](mailto:wsimpso0@our.ecu.edu.au)

If you are willing to participate, please return the Expression of Interest Form included with this letter in the stamped self-addressed envelope by xxxxxxxxxxxxxxxxxxxx.

Thanking you in advance,

**Wendy Simpson**

**Graduate Research Student, Edith Cowan University**

## Appendix B - Expression of interest form

### Expression of Interest to participate in research

**Research title** - Accommodation for adults with an intellectual disability: Exploring the lived experiences of ageing parent carers and the reasons behind their decision to continue to care in the family home.

I ..... have read the invitation letter and Information Sheet regarding the proposed research to be undertaken by Wendy Simpson, Graduate Research Student at Edith Cowan University, and agree to be contacted regarding participating in the study.

I understand that participation is voluntary and I may withdraw at any time.

**Signature** - .....

**Contact telephone** -.....

**Contact email** - .....

**Address** - .....

.....

**I prefer to be contacted by (please tick)**

Phone ☐

Email ☐

By post ☐

**Please return using the self-addressed stamped envelope by xxxxxxxxxxxxxxxxx.**

## Appendix C - Information Sheet

### Research Information Sheet

**Research title: Accommodation for adults with an intellectual disability:** Exploring the lived experiences of ageing parent carers and the reasons behind their decision to continue to care in the family home.

**Name of researcher** – Wendy Simpson, Graduate Research Student

**Name of Supervisor/s –**

Dr Vicki Banham , Senior Lecturer,  
Faculty of Health, Engineering and Science, School of Psychology and Social Science  
Telephone: 6304 5530  
Email:v.banham@ecu.edu.au

A/Prof Trudi Cooper,  
Faculty of Health, Engineering and Science, School of Psychology and Social Science  
Telephone: 6304 5637  
Email:t.cooper@ecu.edu.au

**What is the study about and who will participate?**

I will interview parent carer/s of an adult child with an intellectual disability who remains living at home with them. The study aims to discover the reasons why parents, or a parent, has decided to keep their adult child at home and not consider places in independent accommodation or a group home, what has influenced them to do so, and what plans they may have for the future care of their child when they can no longer care for them at home.

**Why is the study important and who will it benefit?**

The study is important so that the barriers to seeking accommodation may be broken down for current and future service users, and may influence future planning and policy development. All families who care for a family member at home who live with a disability have the potential to benefit from this study.

**Who is conducting the study?**

I will conduct the interviews for the research study. I am a Graduate Research Student at Edith Cowan University. The research is being conducted as a part of the requirements of a Masters Degree in Social Science.

**What will I need to do?**

Once you indicate your interest in participating in the study, and have returned the *Expression of Interest* form in the self-addressed envelope, you will be contacted and a time will be arranged for the interview to be conducted, at the location of your choice. Your family home would be suitable for this.

**How is my privacy guaranteed?**

The interview will be audiotaped and transcribed at a later date, however all documentation will be de-identified and information gathered will remain confidential. Responses will be coded in a number format, and will not use any names or addresses. All recordings and documentation will be stored in a secure location at the university.

**Are there any risks to participating?**

All interviews will be conducted sensitively and in confidence. If you become distressed at any stage you may discontinue the interview and continue at a later date. You may withdraw from the study at any time and any information gathered will be destroyed. In addition, I have information and contacts for counselling or support from independent community organisations. This information will be provided at the time of the interview.

**Do I have to take part, and what is involved?**

Participation is entirely voluntary and you may withdraw at any time without giving a reason. This research is not connected to your service provider and your service provision will not be affected. You will be required to be interviewed for approximately 1 ½ - 2 hours. A second interview may be required.

**Who has approved the study?**

The study has been approved by the Human Research Ethics Committee at Edith Cowan University. If you have any concerns or complaints about the study, please contact - Research Ethics Officer, Edith Cowan University, Phone: 6304 2170  
Email: [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au)

**Who do I contact for further information?**

If you have any specific questions regarding the study, please contact me on 0403355114, or by email at [wsimpso0@our.ecu.edu.au](mailto:wsimpso0@our.ecu.edu.au)

**Can I see the final results of the study?**

If you would like a copy of the results of the study, you can let me know at the time of your interview or by contacting me at any time.

**What do I do now?**

If you would like to participate, you will need to fill in and send me the *Expression of Interest Form*, and you will be contacted and a meeting arranged.

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**Thank you for taking the time to learn about this study and your consideration to participate.** Please keep a copy of this *Information Sheet* and *invitation letter*. If you decide that you would like to participate, please return your *Expression of Interest Form* (enclosed) using the stamped and self-addressed envelope.

Kind regards,

**Wendy Simpson**

Graduate Research Student

Master of Social Science, Edith Cowan University

## Appendix D - Consent Form

### Consent to participate in research

Faculty of Health, Engineering and Science

School of Psychology and Social Science

**Research title** - Accommodation for adults with an intellectual disability: Exploring the lived experiences of ageing parent carers and the reasons behind their decision to continue to care in the family home.

**Researcher** – Wendy Simpson

Contact 0403355114

[wsimpso0@our.ecu.edu.au](mailto:wsimpso0@our.ecu.edu.au)

### **Declaration -**

- *I have read the information sheet provided and have had the opportunity to ask questions. Any questions I have asked have been answered to my satisfaction.*
- *I understand that all information provided is treated as strictly confidential, will be de-identified, and will not be released by the researcher unless required to by law.*
- *I have been shown the questions that I will be asked in the interview, and am aware of the time required to undertake the interview*
- *I am willing to participate in an interview, realising that I may withdraw at any time without given reason and without prejudice.*
- *I am aware that the interview will be the audio-taped and will be transcribed by the researcher*
- *It has been explained to me that audio recording and transcriptions of the interview will be stored securely on the university premises with no identifying names.*
- *I agree that research data gathered for the study may be published, provided no names or other identifying information is used.*

Name of participant .....

Participant signature .....Date.....

*I ..... have explained the research study to be conducted, and the implications of participation and requirements of the study to the volunteer. I believe that the volunteer understands and has given consent to participate.*

Name of researcher .....

Researcher signature.....Date.....



## **Appendix E - Interview questions**

**Accommodation for adults with an intellectual disability:  
Exploring the lived experiences of ageing parent carers and the reasons behind  
their decision to continue to care in the family home.**

### **Central question -**

***What factors influence the decisions made by ageing parent carers of adults with intellectual disability to continue to provide care and support in the family home?***

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*Thank you for agreeing to participate in this interview for the research study I have described. I acknowledge your time taken to read and understand the information I have provided, and the time for this interview. Today we will spend approximately 1 ½ hours discussing choices and decisions you have made regarding the living arrangements for your son/daughter.*

*This discussion will be recorded so I can transcribe at a later date. I may still take notes as we progress through the interview. Your privacy is maintained at all times. The recordings and transcriptions will be identified by code, not by name, and stored in a secure location at the University.*

*There are no right or wrong answers. Please feel free to stop the interview at any time if you are distressed or uncomfortable with the questions. You may withdraw from the research at any time. If you feel that you require counselling or support at any stage, before or after participating in this research, you may contact the following to seek low cost, or fee free assistance –*

#### **CONNECT FOR LIFE**

*AnglicareWA Mental Health Carer Support Ph: 1800 175 055 (area specific support)*

#### **ARAFMI COUNSELLING**

*A free service in nine locations in Perth Ph: 9427 7100*

#### **CALADENIA HOUSE COUNSELLING**

*Post graduate students under full supervision, Murdoch University – Ph: 9360 7848*

#### **CENTRECARE**

*Four locations in Perth, free or low fee services – Ph: 9325 6644 (Perth office)*

#### **FAMILY SUPPORT NETWORK**

*Mirraboooka location - Ph: 1300 760 691*

#### **CARERS WA**

*For enquiries - Carers WA: 1300 CARERS (1300 227 377) 8.30am – 4.30pm*

*Carers Counselling Line: Freecall 1800 007 332 8.00am – 5.00pm*

*For additional assistance with location of support services, contact RUAH COMMUNITY SERVICES – Ph: 9485 3939*

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1. Can you tell me about your son/daughter; your other children; your grandchildren (if any?).
  - a. Can you describe the support your son/daughter needs at home?
  - b. What support do you receive personally to assist with the care of your son/daughter? This may be from family/friends/neighbours.
  - c. What supports do you currently receive to assist *you personally* in the home? This refers to *your* daily living tasks, assistance with health related conditions, home duties and mobility. Do you currently receive aged care services to assist in any of these tasks?
  - d. Are you able to explain to me the support/activities/work that your son/daughter engages in during the day and weekends?
2. Has your son/daughter ever stayed, even for a brief time, in respite or holiday accommodation when you were not present?
  - a. If so, can you tell me about their experiences while out of your care? Are you able to tell me about *your* experiences/feelings while they were in respite or on a holiday away from home?
  - b. If not, what has prevented you from seeking respite or holidays away from home for your son/daughter?
3. What plans do you have in place for when you are no longer able to provide care, for whatever reason? These may be financial plans, accommodation plans, or other plans.
  - a. If there are no formal plans in place, what are your preferred living arrangements for your son/daughter in the future? This may or may not be with family, friends or others. What has influenced your decision to continue to provide care at home?
  - b. If there are plans in place, are you able to share those with me?
  - c. What services would be of assistance for you to help you plan for your son/daughter for their future?

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*Before we finish, is there anything else that you would like to discuss?*

*Thank you for your time and your openness. If you would like a copy of the results of this research you may contact me at any time after the research has been completed and I will provide you with the results and conclusion, or a copy of the final thesis if you prefer.*

*Please keep your copy of the information sheet and informed consent letter.*